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ABSTRACT

The monograph resulted from the Switzer Memorial Seminar which brought together 20 persons recognized for their achievements in rehabilitation. Five action papers formed the foundation for the program: "Social Influences on Rehabilitation: Introductory Remarks" (E. Berkowitz); "Trends and Demographic Studies on Programs for Disabled Persons" (L. Haber); "The Politics of Disability: Future Trends as Shaped by Current Realities" (W. Roth); "Changing Perception of Disability and the Future of Rehabilitation" (H. Hahn); "Ethical Considerations Facing Society in Rehabilitating Severely Disabled Persons" (J. Noble). Each of the action papers is followed by excerpts of reviews and comments made by participants. A summary of recommendations related to the topic of chapter five is given at the end of the document following six brief special papers: "The Competitive Marketplace: A Partnership with the Rehabilitation Community is Needed Now More Than Ever" (A. Colby); "Economics, Rehabilitation and the Post-Industrial Society" (R. Ehrle); "Some Thoughts on Independence" (M. Nosek); "A Response to the 'Changing Perception of Disability and the Future of Rehabilitation'" (L. McConnell); "The Emerging Role of Disabled Hispanics" (A. Suazo). (CL)

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Social Influences in Rehabilitation Planning: Blueprint for the 21st Century

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A Report of the Ninth Mary E. Switzer Memorial Seminar
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A Memorial Tribute

To Mary E. Switzer

1900 - 1971

Few people realize that she had a satisfying and fully successful career in federal government employment that spanned several decades prior to her formal entry into the field of rehabilitation. She was fifty years old when she became director of the Office of Vocational Rehabilitation in 1950, and she brought to the position a superior intellect and ability. Her many talents and experiences in economics, the legislative process, government administration, health, welfare and public education were only a few of the composite assets brought with her. She entered the movement at a crucial point in its evolution. It was a time in which difficult decisions had to be made between maintaining the status quo or moving to a larger and unknown future but with increased opportunity to serve tens of thousands of disabled persons yet in need.

Following a life pattern in support of increased services to people and a more responsive and humanitarian government to changing human needs, she readily committed herself to the less certain but more hopefully expanded future for rehabilitation. The rest is history. The breadth and humanity of Mary Switzer are stamped forever in the passage of Public Law 565 with its research and demonstration features, its concern for rehabilitation education, its mandate to construct necessary rehabilitation facilities, its totally new characteristic of international efforts and cooperation regarding rehabilitation, and perhaps, above all, in its expanded funding base for more personnel and programs for those in need of rehabilitation services. In the years that followed, she went on to even greater legislative and governmental leadership heights in behalf of both disabled and disadvantaged people.

(continued on back inside cover)

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Preface

I am delighted to have the opportunity to greet the Switzer Scholars and as President of the Human Resources Center, I am pleased that we could help sponsor this meeting. I am particularly happy to see that the Seminar deals with public policy because I feel it is critical that professionals in the fields dealing with disabled people play an informed and active role in influencing the Congress, the Executive Branch, and state and local governments in the development of humane and cost-effective programs for disabled persons.

I am pleased that at this reception honoring Mary Switzer, we have the opportunity to present a bust of Mary to her nephew, Dick Switzer, who now serves as Deputy Commissioner for the Office of Vocational Rehabilitation in New York State. I know Mary would be so pleased that Dick has become the Director of the New York State Agency. As an old rehabilitation grantee myself (I directed a Rehabilitation Services Adminstration training grant in Speech Pathology and Audiology at the University of Alabama back in the dark ages of the mid-60's) I was most impressed with Mary Switzer and continued to be even more so when I moved to Washington shortly thereafter. At a "Switzer lecture" I gave several years ago to the Association of Allied Health Professions, I said Mary was a model for public servants with her willingness to draw upon new ideas from the practitioners in the field to help mold effective public policy.

I feel we are at a critical time in public policy in the United States with respect to disabled individuals. While the disabled have made great progress, I feel their status is "fragile" in many ways. There have been centuries of discrimination across many cultures, against persons with disabilities, and the acceptance of disabled persons is still quite new. Their fears can be easily seen when community housing is suggested. To help secure the nation's commitment to disabled persons, we need strong national leadership. Each President beginning with President Eisenhower has favored a federal role in education and rehabilitation of disabled persons. Of late we have heard from those who would like to see vital program budgets cut along with a shift of responsibilities from the Federal to State and local governments. We have witnessed Congressional, professional and citizen resistance to these ideas, but have seen substantial decreases in certain programs for at least some periods of time.

It is my feeling that professionals in the rehabilitation field and in other fields serving disabled persons need to help the American people decide what roles **they hope the federal government will play** in helping provide the services necessary for disabled people to be independent. Clearly the rehabilitation program has been cost-beneficial to the taxpayers and has resulted in millions of disabled citizens leading lives of productivity marked by self-respect.

This was the spirit in which Mary Switzer served in the federal government. It was the spirit in which I was privileged to serve under Presidents Johnson, Nixon, Ford and Carter, and I hope it will be the spirit which will continue into the future. You, as enlightened citizens, can help shape our national policies.

Your work to help disabled persons based on a commitment to them on the part of the American government is in the best spirit of the American character. By affirming our compassionate and caring nature and our belief in helping individuals to help themselves, we enrich the lives of disabled citizens and enrich each citizen. We help to live out the American dream which is symbolized by the Statue of Liberty with its promise that we are a country that **cares for each citizen** and which provides the opportunity to succeed.

Edwin W. Martin
President and Chief Executive Officer
Human Resources Center

Sponsors of the Ninth Switzer Memorial Seminar & Monograph

★ ***Human Resources Center***
Albertson, New York

★ ***New York University,***
Department of Rehabilitation Counseling

★ ***Postgraduate Center for Mental Health,***
New York, New York

★ ***President's Committee on Employment of the Handicapped,***

★ ***World Rehabilitation Fund, Inc.***

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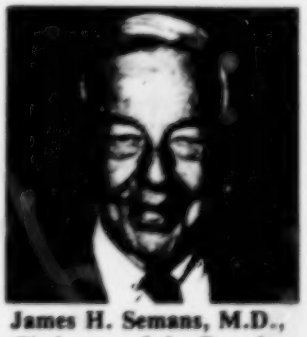

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Introduction

"In rehabilitation, as in all social programs today, time presses in on us. National and world movements outside our own specific concerns and challenge us to be alert to the obligation the rehabilitation community has to share its technology, its philosophy, its commitment and even more, to insist that rehabilitation play its maximum eloquent role in the development of public policy and be the probing conscience of private and voluntary movements to help those in need of service."

Mary E. Switzer

These words were spoken by the late Mary Switzer, for whom the Switzer Memorial Seminar is named. These eloquent words, although stated in 1970, could easily have been delivered at the Ninth Seminar because of their relevance to the topic of rehabilitation planning as influenced by social change and pressures in today's world. As we move into the second half of the 1980s and prepare for the last decade of the Twentieth Century and beyond there are three major areas of change that will help shape our course. These include the changing nature of **work**; the changing nature of **disablement** and the changing nature of **society**.

The planning committee, in outlining the goals of the Seminar, provided some very broad parameters for the Switzer Scholars as they pursued this project. Some examples of the subtopics to be covered included the following:

- *The economic basis of decision-making in the development of rehabilitation roles and functions.*
- *Economic and cultural influences on public policy toward persons with disabilities.*
- *Long term care and support programs.*
- *The shifts from public to private sector initiatives.*
- *Changes in the ages of populations to be served.*
- *Social policy and the grass roots or consumer movement.*
- *Positive and negative elements in current laws affecting disabled persons and their families.*
- *Problems and issues as a result of the trend of deinstitutionalization.*
- *The expanding role of business and industry in hiring qualified workers having a disability.*
- *The effects of the new technologies in the area of service delivery and direct usage by disabled persons themselves.*
- *How political movements and philosophies will shape rehabilitation programming.*

The above represented some of the issues that would be discussed at the Seminar. Many of the feelings, ideas, and recommendations that emerged from the three days of deliberations are found in this monograph. We do not expect everyone to agree with all of the contents. The group of scholars represented wide ranges of opinion, background experience and training. We do expect that the contents **will stimulate interest and action** in terms of enhancing the lives of those persons needing a broad range of services and sensitivities to insure their **full citizenship and independence.**

The Switzer Memorial Seminar brought together twenty persons designated as "Switzer Scholars" from around the nation. They were selected because of their interest in the area under study as well as their accomplishments and leadership as it concerned the rehabilitation and habilitation of persons with disabilities.

The Seminar was held in New York City, November 28-30, 1984, and was co-hosted by New York University's Department of Rehabilitation Counseling and the Human Resources Center of Albertson, N.Y.

Welcomes were provided by Betty Hedgeman, NRA President; Jerrold Ross, Dean of Academic Affairs at NYU; Pat Dvonch, Chair, Rehabilitation Counseling Department, NYU; Valerie Ellien, Rehabilitation Counseling Department, NYU; Jack Victor, Human Resources Center; Richard Switzer, Deputy Commissioner of Rehabilitation, Department of Education, State of New York; and Richard Englehardt, RSA Commissioner of Region II.

At a special reception honoring this year's Switzer Scholars, Edwin Martin, President of Human Resources Center, presented a bust of Mary Switzer to Richard Switzer, her nephew. On hand at the reception were several former Switzer Scholars/Fellows and colleagues of Mary Switzer, including Howard A. Rusk, M.D., World Rehabilitation Fund, Chairman, who provided a memorial tribute to the great Miss Switzer.

Format of the Seminar and Monograph

Action Papers -- The Foundation of the Seminar

Five **Action Papers** were written specifically for this Seminar and provided a foundation for the program. Deliberations centered around the following papers:

- *Social Influences on Rehabilitation Planning: Introductory Remarks. -- By Edward D. Berkowitz, Ph.D.*
- *Trends and Demographic Studies on Programs for Persons with Disabilities. -- By Lawrence D. Haber.*
- *The Politics of Disability: Future Trends as Shaped by Current Realities. -- By William Roth, Ph.D.*
- *Changing Perceptions of Disability and the Future of Rehabilitation. -- By Harlan Hahn, Ph.D.*
- *Ethical Considerations Facing Society in Rehabilitating Severely Disabled Persons. -- By John H. Noble, Jr., Ph.D.*

The Action Papers, designated as chapters in this text, were sent to all "Switzer Scholars" in advance of the seminar. Reviews of each paper were completed prior to the seminar and served to prepare the Scholars for the three days of intensive deliberations on the subject under study.

The seminar provided a forum to discuss each of the basic issues in depth. This was accomplished in both plenary sessions and small group work sessions that focused on each "Action Paper." The three day program of intense interaction culminated in a number of recommendations for action in the areas of policy and program development, service delivery, research, training and legislation.

Format of the Monograph

The format of this monograph closely follows that of the seminar itself. Each of the five "Action Papers" are shown as a chapter and include a section on "Reviews and Comments" of each paper made by the participants. At the end of each chapter, where appropriate, there is a summary of recommendations for action in easy to use style.

In addition, invited "Special Papers were developed by some of the Switzer Scholars and other prominent persons and are found in a special section of this monograph.

Acknowledgements

The Mary E. Switzer Memorial Seminar and the monograph of the proceedings were made possible by a great many people and their organizations dedicated to the independence and rehabilitation of persons with disabilities. It should be noted that funds were initially raised by a special committee of the National Rehabilitation Association (NRA) known as the Switzer Memorial Fund Committee, which was guided by Mrs. Olive K. Bannister.

Thanks are expressed to all who played some part in the planning and implementation of this memorial tribute to Mary E. Switzer. Special appreciation is expressed to the following persons:

The Switzer Memorial Committee members: Betty Hedgeman, Edwin Opheim, Joseph H. Owens, Jr., and Steve Zimmerman.

Also to: NRA Past President Thomas R. Gaines, NRA Executive Director David Mills, and members of his staff Dick Dietl, Judy Harris and Gloria Scott. Their support and assistance was always there when we needed it.

Special appreciation is expressed to the following:

The host organizations -- Dr. Pat Dvonch and Dr. Valerie Ellien of New York University; and Dr. Edwin Martin and Dr. Jack Victor of the Human Resources Center; and of course, to the Switzer Scholars for their time and expertise in making the Seminar a memorable one. It is the hope of the Switzer Memorial Committee that the report of the Ninth Memorial Seminar will help to foster better understanding and improved services to those individuals to whom our energies are dedicated.

Scholarly Observations of the Seminar

This Memorial Seminar sparked numerous debates and many ideas were expressed about a wide range of issues that will help shape the direction of rehabilitation services in the years to come. The following quotes from Switzer Scholars provides an overview of the seminar:

All human beings have the potential to be "disabled" or "handicapped" at any given point in time, which is beyond the control of the individual. We need to keep this perspective in mind when developing public information policy, training and research.
-- William A. Calzaretta

Older persons are a minority, and one that has been studied extensively. Research on older disabled persons, however, is of relatively recent advent. Many persons become disabled for the first time in old age, while others grow old with one or more disabilities and must adjust to the additional limitations imposed by age-related illness and disease. More research is needed on both types of individuals, especially during the mid-life period. Data on middle-aged disabled people can help us in planning needed services for both mid-life and older disabled individuals.
-- Jane E. Myers

Probably more importantly than with any other minority group, the question of terminology with regard to persons with disabled individuals operates as a strong counter-productive force in achieving access to employment. Disabled persons have not yet adopted and identified a terminolgy which connotes self-pride and self-worth.
-- L. Robert McConnell

If dramatic breakthroughs are to come in the next 15 years, there must be daring conceptualization and action. Incrementalism will wear everybody down. Why not turn disability and the disabled into something that is valued in America? Why not make disabled people an economic asset for employers and able-bodied workers who are fortunate enough to work in the same firm with disabled workers.
-- John H. Noble, Jr.

While all who read Dr. Hahn's paper will undoubtedly agree with and applaud his championing of the minority model of disability, we would also undoubtedly agree that it is better not to have a disability than to have one, and that it is better to be in the majority that the minority. On these grounds, I propose that we not seek to abandon the "functional limitations" model, but rather seek to adapt it to the concepts underlying the minority model. I further propose that the real enemy is the care-giving model.
-- Margaret A. Nosek

Most medical situations are apprcached ethically, first with professional information, formulated so that the meaning of the words used are familiar to the patient. Following this the patient should have an interpretation of this information by another person amicable to the patient, preferably one who has lived with that ethical decision, e.g., a rehabilitated paraplegic.
--James H. Semans, M.D.

By the end of this century the Hispanic population will be the largest minority in the country. Due to cultural and language barriers, Hispanic persons with disabilities have been largely excluded from rehabilitation programs. Because they are both disabled and Hispanic they are often in "double jeopardy" and face many problems in accessing rehabilitation networks in the United States. It behoves the rehabilitation movement to recognize this growing segment of our population and to develop outreach programs and train personnel to be more effective and sensitive with this clientele. Realistically this should include the training of more bilingual and bicultural professionals to do the job.
-- Antonio C. Suazo

In order to prevent premature obsolescence, the rehabilitation counseling profession needs to acknowledge a partnership with its consumers. Together with the community of persons with disabilities, the rehabilitation counseling profession strives for a world where the effects of disabilities are negated or minimized. The rehabilitation counselor is a highly trained professional who offers consumers alternatives for optimizing their interaction with their environment.
-- Edna M. Szymanski

NRA President's Message

When I hear the name Mary Switzer it brings to mind excellence in rehabilitation and the highest level of people caring about other people. Mary Switzer embodied the notion of human beings working for and with others toward the loftiest of ideals, independence, dignity, self-esteem. In addition to these qualities, Miss Switzer was a manager of unusual quality. She understood the giant bureaucracy of government and was able to develop a bi-partisan coalition spanning the U.S. Congress and the Executive branches of government.

From Presidents to Members of Congress, Mary Switzer was able to communicate the pressing matters of the day and these were translated to programs across the land, programs that affected disabled persons everywhere.

It has been more than a decade since Mary Switzer has died, yet her writings and ideas have even more relevance today. Social changes are occurring all around us, new movements have arisen. Consumers have not only more of a voice in the affairs of the world, but are more active than ever before in shaping their destiny. At the same time, Vocational Rehabilitation as a profession has grown enormously. There is a substantial body of knowledge, well established training and continuing education programs and a fair-sized number of professionals doing the job of rehabilitation. Even so we are at a crossroads in rehabilitation ready to take on the new challenges that are shaped by the passage of time.

This monograph provides a number of stimulating ideas that need to remain carefully in view as we prepare for the next decade and beyond.

The Scholars' discussions, conclusions and recommendations enhance the memory of what Mary Switzer has signified throughout the years. The National Rehabilitation Association is grateful for the opportunity to present this to you and looks forward to your continued participation and support.

Betty Hedgeman, Ph.D.
President, NRA

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Switzer Seminar Committee

Gary F. Austin, Ph.D.
Chairperson/Co-Editor
Switzer Seminar Committee

SPECIAL MOMENT: Dick Switzer, Deputy Commissioner of DVR for New York (far left) warmly greets Dr. Howard A. Rusk (far right), one of the great movers for rehabilitation, both with Mary Switzer and since. Sharing the meeting were Edwin Martin, President, Human Resources Center (left center) and Richard Englehardt, Commissioner of RSA's Region II.

GREETINGS: Dean Jerrold Ross, New York University, greeted the Switzer Scholars. NYU co-hosted the event with the Human Resources Center.

Seminar Scenes

A LIVING PIONEER: Monroe Berkowitz had much to smile about. He was one of the first Switzer Scholars in 1975 and witnessed his son's (Edward) work on the Ninth Seminar.

GETTING UNDERWAY: Jack Victor, a former Scholar from the Human Resources Center (co-host of the event), brought a special greeting to the assemmbled Scholars at the opening session.

Switzer Scholar Berkowitz

Chapter One

Social Influences On Rehabilitation Planning: Introductory Remarks

By Edward D. Berkowitz

Seminars of this type provide room for speculation. If these particular speculations stray too far beyond the bounds of the evidence, I am confident that other participants will not hesitate to challenge them. I see my role as introducing the other seminar papers by placing rehabilitation and disability policy into a historical context. I wish, therefore, to talk about the concept of disability policy, to show how certain policies do not achieve their stated objectives, to discuss the historical underpinnings of the rehabilitation program, and to isolate the trends that I find most relevant for the future.

Disability as a Heterogeneous Concept

Part of the difficulty we have with disability policy is that the notion embraces such a wide range of programs and ideas. The programs begin with different rationales, and they use different methods to reach their objectives. Once in place, the programs quickly become part of the institutional landscape and make the process of reform more difficult.

Furthermore, the reform process often begins with a misconception. It seizes on a definition of disability and bases its recommendations on that definition. Such an approach fails to comprehend that disability itself means at least three different things.

On one level disability refers to the damages that one group of people collects from another as a result of an insult or injury. Although the courts and litigation serve as the usual means of transferring money from the responsible to the disadvantaged, many other mechanisms exist for this purpose. Private insurance and social insurance come to mind as do specific disability programs that use a combination of these approaches. Workers' compensation, for example, illustrates the oldest form of social insurance that pays damages to a group of disadvantaged people. In addition to workers' compensation, the damage principle lies behind modern concerns such as asbestos claims, claims for agent orange, and claims that arise from automobile accidents. In each of these cases, disability has become a short-hand for damages.

On the second level, disability means the state that lies between ill health and unemployment. If an impairment forces someone from the labor force, that person collects disability. The person is neither sick nor unemployed: he or she is disabled. This second level, like the first, gives rise to many policy devices and program. In some cases, for example, a person's employer may pay him disability; in other cases, the federal government, acting through the social security system, makes the payment. Whoever makes the payment often has a difficult time administering the relevant program. Because the distinctions between ill health, unemployment, and disability remain so vague, the problem of differentiating among them poses dilemmas as complex as any in public policy.

Perhaps these subtleties require a concrete illustration. One might consider a case from the files of the Social Security Administration. In August of 1953, a coal miner received a notice that he had been laid off from his mine. For the next two years, the miner scratched out an existence as a tenant farmer. Although the miner had contracted polio

as a child, he had never been treated for it. In February of 1957, however, he entered a hospital, and the doctors found many things wrong with him. He had high blood pressure, and he was often short of breath. The doctors also described him as very nervous. By now the miner was sixty years old, broken down and unable to find a job.

Like others in this state that lay between ill health and unemployment, the miner could be treated in a variety of ways. In his particular case, the miner got unemployment insurance when he left the mines. When this benefit ran out and when his attempt at farming failed, he received benefits from public welfare. At one point he tried to receive rehabilitation from the vocational rehabilitation agency, only to be told that he "lacked interest." At the age of sixty, he made a bad rehabilitation client. His problems appeared too fundamental for the rehabilitation process to overcome, yet the alternative of income maintenance also proved difficult for the miner to obtain. Social security wanted to maintain a clear distinction between unemployment and disability. It hesitated to let the coal miner retire because it did not regard the deteriorating situation in the mines as its responsibility.

When disability means the state that lies between ill health and unemployment, society faces a choice between income maintenance and rehabilitation. A person can receive a pension to cope with his disability or he can receive a course of training to overcome his disability. In cases that involve older people with relatively few skills, people who might be considered the pre-old, the choices become narrower. Rehabilitation appears a less realistic alternative, and retirement emerges as the more likely choice. As the demand for the retirement rises, however, the pressures to limit the tickets out of the labor force become stronger and society seeks to draw tighter lines between disability and unemployment.

These two meanings of disability, as damages and as the link between ill health and unemployment, often overlap with one another. The more well-defined a disadvantaged group, the fewer tests its members need to pass to get disability payments. Persons who are blind who choose not to work face an easier time getting disability benefits than do unemployed coal miners. Blindness in this sense become a short-hand for disability that combines both meanings of the term. On the one hand, blind individuals collect damages from their employers or from society because they are deemed to be disadvantaged as the result of their inherent condition. On the other hand, the condition of blindness is considered sufficient for someone to drop out of the labor force on the grounds that he or she is disabled. In this second sense, the condition of blindness hastens the transition between ill health and unemployment. Much the same could be said of veterans with war-related impairments. A veteran may collect damages, and he may also be permitted to leave the labor force sooner than his civilian counterpart struggling with ill health and an uncertain labor market.

Just as the meanings of disability merge into one another, so do the policy structures that interpret these meanings. Courts serve as mechanisms for collecting damages, and income maintenance programs operate to aid people who are unemployed as a result of ill health or, to use the more elegant sociological term, functional limitation. Although the income maintenance programs seek to put an end to the more uncertain method of litigation, each income maintenance program creates disputes that produce litigation. Rehabilitation and income maintenance represent alternative approaches to the problem of disability, yet one depends on the other. Persons who undertake rehabilitation need money to tide them over during their training period and during any subsequent periods of unemployment.

For all that the meanings and the policy structures shade into one another, a third distinctive meaning of disability policy suggests itself. Disability policy also concerns policy that relates to persons who have handicaps. These are people who were born with or who acquired a mental or physical impairment or limitation in function that immediately identifies them as belonging to a distinctive group of individuals. The group's distinction lies in its physical or mental appearance or performance. Persons with developmental disabilities and spinal cord injuries come immediately to mind.

In each of the first two definitions, disability involves an element of choice. The third differs from the first two in that persons with disabilities do not choose to be handicapped; society imposes this label on them. Public policy toward this group has undergone a major transformation from custodial care, such as a residential facility for those who are mentally retarded or blind, to self-care, such as training for independent living. The people affected have gone from being objects of care to being consumers of services. These distinctions, which have developed over many years and relate to many other societal changes, have created a new interest in civil rights legislation that permits persons labelled handicapped to participate in the society around them. In this third sense, then, disability means handicap.

Since disability means so many things, it becomes

difficult to speak of a universal disability policy. People who wish to gain influence over this policy often base their recommendations on a particular meaning of disability and have a particular model of a disabled individual in mind. Under the first meaning, they may envision a person suffering from cancer as a possible result of exposure to asbestos or they may picture a worker with a broken arm suffered on the job. Under the second meaning, they may picture a tired and demoralized 55 year old who is beginning to let nagging health problems, a bad back perhaps, ease him from the labor force. Under the third meaning, they may envision a person in a wheel chair who desperately wants to enter the labor force and who seeks an employer with an open mind. Each of the meanings produces a different picture, and each of the pictures represents a different situation.

We should not expect that a policy that will benefit one person will benefit another. We should also not be surprised that, with such a broad concept and with so many different meanings to consider, the nation maintains so many disability programs and that they sometimes overlap with one another. Nor should it come as a surprise that a policy that addresses one of the meanings of disability or one of the policy interpretations of disability produces unintended consequences as it conflicts with another meaning of disability and another policy interpretation.

Some Unintended Consequences

Two illustrations reveal some of the unintended consequences of disability policy. The first concerns disability insurance, the nation's most important and largest disability program. Begun in 1956, this program comes closest to the second meaning of disability. It seeks to aid people who are unable to engage in substantial gainful activity because of a medically demonstrable impairment.

Because so many people realized the subjectivity of this meaning of disability, the creation of disability insurance took many years to achieve. Only the great popularity of social security made the program possible, and even with this popularity, the disability insurance program contained many political concessions to people who remained skeptical about its viability. Chief among these concessions was placing initial decisions about disability on the state level, in most states in vocational rehabilitation agencies. The argument made at the time concerned the cautious approach that the states would take and the constructive approach that the rehabilitation counselors would bring to disability insurance.

Neither of these things materialized. Instead, the actions produced unintended consequences. State disability examiners developed separate specialities from rehabilitation counselors. States showed no particular caution in declaring someone disabled. They realized that the alternative was often welfare rather than rehabilitation and that welfare would cost the states more money than would disability payments from social security. The most significant of the unintended consequences occurred in 1983. The states had such disagreements with the Social Security Administration in that year that they refused to remove people from the disability rolls.

The situation in Marland was instructive. The director of the Maryland program said that requests from the Social Security Administration to review cases had caused his agency to fall behind in its workload in 1983. To overcome this problem, the state director hoped to shift rehabilitation counselors to the job of disability examiner. The reason for the surplus of rehabilitation counselors was the passage of the Omnibus Reconciliation Act of 1981, which ended the Beneficiary Rehabilitation Program that had acted as a subsidy for Maryland's vocational rehabilitation program. The director soon discovered, however, that the jobs of rehabilitation counselor and disability examiner were so different that the rehabilitation counselors required special training to make decisions on eligibility for the disability program. That took time and added to the backlog.

Here, then, was a case in which the reality of the situation in disability policy differed from the rhetoric. Rehabilitation and income maintenance were different and demanded different skills from government workers; the idea of blending rehabilitation and income maintenance as had been envisioned in 1956 never materialized. In 1956 policymakers held an image of disabled persons that emphasized the link between ill health and unemployment. They implicitly believed that a simple adjustment might transform these people into labor force participants; they appeared to think that the people suffered temporary conditions that might be alleviated. In reality, the program, initially limited to those over 50, accepted people who might better be categorized as the pre-old: people who wanted retirement. Since the two images were incompatible and since the second image approached a little closer to reality, the policy of rehabilitating disability applicants failed and produced unintended consequences. The second illustration concerns the relationship between mentally impaired individuals and disability insurance, between a system based on damages and one bas-

ed on more stringent standards of entitlement, and between conceptions related to income maintenance and conceptions related to civil rights.

In the spring of 1983 the Senate Committee on Aging highlighted the problems that mentally disabled individuals faced in the review of people on the disability rolls. Disability insurance relied on a tough definition to protect the public against an explosion in the rolls. Furthermore, disability insurance and Supplemental Sceurity Income were linked by a common definition and certification procedure. Problems of disability insurance often became problems in Supplemental Security Income as well. Policy in the field of mental health, never given the same clear statutory statement as in the disability insurance program, relied on deinstitutionalization. Much of this policy involved removing people from the state asylums, centers of cold custodial care, and putting them into what President Kennedy had once described as the open warmth of the community. Once in the community, however, they required income support, and the logical sources of this support were disability insurance as well as supplemental security income. The law, however, made no exceptions for deinstitutionalized mentally ill persons. It applied the same tough standard to them that it did to everyone else.

Furthermore, mental illness, like lower back pain, represented one of the disability insurance program's classic dilemmas. The earliest drafts of the legislation, for example, contemplated excluding mentally ill persons from the program. With the introduction of psychotropic drugs, the conditions of many patients could be stabilized, yet their conditions fluctuated widely over time. If a person's emotional state resembled a pendulum that swung from manic to depressive, a person might see the disability examiner just as his condition was passing through the normal range. Even though the patient's prognosis might be poor, his or her condition appeared normal. Even for disability insurance, the regulations that applied to this population were particularly tough. Someone with schizophrenia, for example, needed to demonstrate "marked restriction of daily activities and constrictions of interest and seriously impaired ability to relate to other people."

That meant that people capable of watching television might not meet the standard of a "marked restriction of daily activities." One medical consultant noted that it was "practically impossible to meet the listings...for any individual whose thought processes are not blatantly psychotic, or is not having a psychiatric emergency requiring immediate hospitalization."

Considered in and of themselves, the problems of getting benefits to mentally ill persons made it difficult for program administrators to formulate policy. The difficulties became more pronounced in the face of pressure from legal advocates to secure benefits for them. Of all the sectors of disability policy, mental illness and mental retardation had the strongest links to the legal community. The deinstitutionalization movement originated, in part, from the efforts of lawyers to secure the civil rights of the mentally ill. When the crisis in disability insurance and Supplemental Security Income broke in 1981, it seemed natural for groups concerned with mental health and developmental disability to turn to the lawyers. These lawyers, comfortable in the role of exposing unfair treatment, brought various horror stories to the attention of the press and the politicians.

In the spring of 1983, therefore, horror stories told by those with mental impairments became part of public policy related to disability. A Baltimore newspaper wrote of Martin Gladstone, whose anchor to mental stability was built on psychotropic drugs, counseling and close daily supervision. Gladstone found a letter in his mailbox that told him he was off the rolls, able to work. For 13 years Gladstone had lived in the Spring Grove State Hospital; now he would be expected to survive in the community, without the support of disability insurance or Supplemental Security Income. The paper quoted a mental health worker as saying the "deinstitutionalization movement will disintergrate." The worker worried that Gladstone would disappear into 'the netherworld of street life."

In this manner one component of disability policy defeated another, and one image or meaning of disability conflicted with another. A policy change that operated using one meaning of disability produced unintended consequences for policies that employed another meaning of disability. Policymakers wanted to guard against too many people using ill health as a means of getting disability, of putting themselves in the transitional state between ill health and unemployment. Applied to one segment of the population, the resulting policy defeated efforts to aid persons with disabilities by providing them with the means to remain outside of the insititution.

The Historian and the Programs

What can historical analysis add to this confusion? At the risk of creating still more confusion,

a historian might suggest that the nature of disability programs change more slowly than do fashions in disability policy. Programs, conceived with a particular idea of disability in mind, have distinctive identities that reflect the eras of their origins. Policymakers, it should be emphasized, do not operate on the level of images and metaphors. Instead, they work with the concrete structures created by distinctive programs. Disability policy, therefore, needs to be discussed at the program level.

The best way to identify these programs is to place them in their historical context and to identify their initial objectives. In this manner, workers compensation concerns the fear of socially destructive and economically wasteful litigation produced by work accidents at the turn of the century. Vocational rehabilitation bears the imprint of the optimism of the twenties. Disability insurance borrows many of its features from social security as that program developed after 1939, and more recent programs, such as the Education of the All Handicapped Act, owe much to modern notions of deinstitutionlization and civil rights.

A historian also knows that programs have difficulty in changing the attributes they acquire in the early years of their operation. Policymakers may want old programs to achieve new objectives, such as the effort to blend income maintenance and vocational rehabilitation in 1956, yet desire and outcome are not the same thing.

Features of the Vocational Rehabilitation Program

For the purposes of this seminar, the vocational rehabilitation program assumes the most importance. It plays a pivotal role in modern disability policy. At the same time, the characteristics that this program acquired in the early years of its operation are still visible. These characteristics often create barriers that prevent the achievement of modern objectives.

At least three of these characteristics come to mind. The first involves what the program administrators of the twenties called "susceptibility." In a classic discussion of vocational rehabilitation, two experts explained this concept with reference to the problem of age. "When a disabled person is past the normal working age," they wrote, "it is usually futile to consider him a possibility for retraining." Certain types of disability, combined "with a certain type of mentality and temperment" made the chances of success so slight as to warrant the agency spending its money on "more promising cases." As a general rule if a persons was not "responsive from the first," he or she might be labelled infeasible and denied services.

The second inheritance from the nineteen twenties involves the program's use of psychology and vocational guidance. In the name of science, a form of science considered quite advanced in the psychologically conscious twenties, agency personnel began to explore the limits of a disabled person's destiny. One rehabilitation anecdote from the twenties told of a man who suffered from a hand injury. The man came to the state agency and made a good impression. He appeared intelligent. Asked to express his preference for employment, he said he wanted a white collar job, something like bookkeeping or office work. The agency checked his educational background and found that he had failed to reach the eighth grade. Confronted with this lack of achievement, the man gave a plausible excuse. Just to clear up any doubts, the state director gave the man some of the new tests. Science reached a verdict. The tests disclosed "a mentality too low for continuous book work and mental work." So the man was trained in a manual line.

The striking aspect of this story was that the tests were taken so seriously. In this case, they detected a man who was attempting to masquerade as a member of the middle class and unmasked him. The tests and the use of psychology in general provided the program with another means of selecting its caseload and of adjusting the disabled person's outlook to coincide more closely with that of the program.

The third inheritance from the twenties, the use of cost-benefit analysis, also reflected the program's selectivity, as well as the program's desire to market itself. The modern concept of entitlement had not yet been invented. Social welfare programs, particularly those that represented innovative uses of federal funds, had to prove their value to society. One way to do that was to conduct cost-benefit demonstrations. This practice, in turn, enabled the program to profit from the mania for investment during the twenties.

Vocational rehabilitation, therefore, became an investment in a disabled person's future, and in this manner the program distinguished itself from workers' compensation and other disability programs. Of all the inheritances from the twenties, cost-benefit analysis proved to be the most enduring. At any point in the program's history one could find the rhetoric or cost-benefit analysis among the official program documents.

As an example, one could cite a speech that Oveta Culp Hobby, Eisenhower's Secretary of Health, Education, and Welfare, made in 1953. She told her audience that it cost $600 a year to maintain someone on public assistance. On the other hand,

it only cost $560 to rehabilitate the average person into gainful employment. The government came out ahead on the deal and as the years went by, the savings mounted. For each dollar the government contributed to rehabilitation, it got back $10 in federal taxes alone. In 1952, according to Hobby, the federal government spent 19.7 million dollars on rehabilitation and rehabilitated 64,000 people. Within a year these people paid more than 10 million dollars in federal income taxes. Hobby concluded that vocational rehabilitation was a better buy than "the most golden of guilt edged stocks. I have used this argument because all too often the layman...thinks of this program as only a Good Samaritan program...but it's also a very practical Samaritan endeavor and deserves respect."

Challenges to Vocational Rehabilitation

Over the years the program won that respect. The rate of its appropriations rose precipitously, and it became one of the great success stories among social welfare programs. At the same time, it faced a series of challenges that revealed the sorts of pressures that all disability programs faced.

In 1943, for example, the program needed to make its peace with both the tradition of special favors to veterans and the development of rehabilitation medicine. Soon after Pearl Harbor, President Roosevelt called the leaders of the rehabilitation community together and asked them to expand the nation's efforts in rehabilitation. It soon became clear that he expected the veterans and civilians to work together. Unlike the first world war, he wanted the second world war to produce a new law that applied both to veterans and civilians. For all of the President's political clout, he failed to get this law. Instead, veterans benefited from a special rehabilitation law that applied only to them.

The civilian rehabilitation program also received a boost during the second world war. For the first time, the program received federal funds to subsidize medical care that might eliminate a person's employment disability. Although this authorization appeared to give federal approval to rehabilitation medicine, it failed to change the basic nineteen twenties structure of the program. It took the dynamic leadership of Mary Switzer and her constant encouragement of rehabilitation medicine to alter established practice. Not for the first time, the federal office moved ahead of the state programs, pushing them to accept the latest medical technology, even if that technology lowered the total number of rehabilitations the state agencies were able to achieve. In 1954 a new rehabilitation law made it possible to expand rehabilitation medicine and traditional rehabilitation at the same time.

The challenges that arose in 1973 were not disposed of so easily. By this time, the program structures from the nineteen twenties were coming under heavy attack. Critics argued that these structures gave the program too conservative a cast. The emphasis on employment limited the program's horizons. By thinking more boldly about disability and the needs of disabled persons, the program might aid the deinstitutionalization movement. Instead of rehabilitation ending in employment, it might concentrate on the goal of independent living. Furthermore, this concept of independence implied an independence from what increasingly militant members of the disabled community called the "dominance" of professionals. No longer did the disabled need to accept the counselor's version of their destinies. As consumers, the persons with disabilities had the right to pick and choose.

Ed Roberts, the former director of the California rehabilitation program and the recent MacArthur Fellowship winner, expressed the ideas that lay behind independent living eloquently during a 1978 Congressional hearing. He said that the idea of independent living centers came from "our experience directly, our experience of trying to survive away from the institutions, away from isolated experiences." "All disabilities come together," he continued, "and learn with each other so that we are not constantly caught in categorical kinds of aids when you are aiding a cerebral palsy person or a very old person. People come together and can talk...about each other's experience." For all of this euphoria, Roberts put his arguments in terms that were compatible with the vocational rehabilitation tradition. He said that severely disabled persons would reach employment but would take them longer than the usual vocational rehabilitation client. "I really believe in outcome and in measuring outcome," he said, "but we have a national commitment to work toward...deinstitutionalization... We need to take a hard look at the law...and take some of the pressure off rehabilitation agencies by creating a stream of independent living." A mandate for independent living would "help rehabilitation agencies tremendously." The cost-benefit ration would still be high, "but it would be a longer term bill."

Independent living came hard to vocational rehabilitation. The 1973 law marked no more than a beginning with its grand rhetoric but vague policy measures to reach severely disabled persons. It took until 1978 for independent living centers to be in-

cluded in the law, and even then not all of the independent living components of the law were funded.

Just as the notion of rehabilitation medicine met with an initial resistance, so did independent living. Both represented changes in vocational rehabilitation tradition that proved difficult for the program to accommodate. Both held the potential to concentrate resources on one case and to lower the number of rehabilitations the program might achieve. Both tended to take power away from the rehabilitation counselor. In the first case, this power passed to the rehabilitation doctors, and in the second case to disabled persons themselves, who might engage in such practices as peer counseling.

At the same time, the two challenges to traditional rehabilitation differed dramatically from one another. The first reflected the modern mania for professionalization, something that was in and of itself not incompatible with rehabilitation. The program strived to become more professional in the forties, fifties, and sixties, in the face of criticism that the counselors lacked formal training and knew nothing of modern rehabilitation technology. In the seventies, however, the conventional wisdom changed. The training and ideology of the counselors, in this new view, stifled the initiatives of persons with disabilities and failed to comprehend the need for civil rights. According to this critique, the counselors continued to adjust the persons with disabilities when it was society that required the adjustment.

Faced with these contrary challenges, the vocational rehabilitation program has attempted to adjust. Despite these adjustments, the program's core identity, as defined by the characteristics it acquired in the nineteen twenties, remains in place. The same could be said for the other disability programs. Each has an identity that gives it a certain inflexibility in pursuing modern objectives. As new objectives arise, new programs get placed on top of one another, further complicating the institutional landscape and making public policy toward disability more difficult to comprehend.

Future Trends

That raises the question of future trends in disability policy. Here again three trends suggest themselves. The first concerns a shift, at least in the short-run, from relying on the public sector to provide rehabilitation services toward experimenting with the private sector. Many large companies, for example, handle their own workers compensation, and many others offer permanent disability insurance as part of their fringe benefits. These large companies and the insurance companies are potential consumers of rehabilitation. They hold no particular stock in the public program and, therefore, many private programs have developed to meet their needs. In a state such as Michigan, for example, the auto makers may use private rehabilitation facilities to aid in a worker's recuperation, and even the state workers' compensation program may send its clients to a private facility.

Despite this trend toward the private sector, there has been a major effort to strengthen the concept of entitlement in the income maintenance programs. In 1980 Congress passed a major disability insurance law that attempted to lower the wage replacement rate reflected in a person's benefits and to encourage disability beneficiaries to re-enter the labor force. In 1984, after a political battle of titanic proportions, Congress reversed itself. It declared that no one could be removed from the disability rolls unless his medical condition had improved. The notion of rehabilitating workers and of limiting the growth of entitlements faded from public view. In the short run, therefore, the emphasis in public policy has been placed on entitlement through income maintenance rather than on rehabilitation. The end of the beneficiary rehabilitation program reinforces this emphasis.

The third and final trend also contradicts the other trends. There continues to be an emphasis on the civil rights of persons with disabilities on independence, on desegregation, and on deinstitutionalization. This trend forms part of a much larger trend that began early in the twentieth century with the movement away from the asylum as an instrument of progressive social policy. The movement continued in the forties and fifties with the end of Jim Crow laws in the south. Among the disabled community, this movement has culminated in the civil rights sections of the Vocational Rehabilitation Act of 1973 and the creation of independent living centers.

This last trend pushes against the first two. The private rehabilitation movement bears a close relationship to the notion of managing disability in the workplace., The civil rights movement attempts to deal with disability in the community. The new reassertion of entitlement centers on tickets out of the labor force for the pre-old; the new emphasis on civil rights emphasizes tickets into the labor force, although many advocates see no contradictions between income maintenance and employment.

Where, then does that leave the seminar as it contemplates social influences in rehabilitation planning? I am not sure where it leaves this seminar, but

it leaves me with one last application of the tyranny of the rule of three. We need, I think, to remember three things.

The first of these things is that programs have limits. Although all generalizations are false, I think that all programs have difficulty in stepping outside of their historical identities. The limits of programs are important to the planning process.

The second of these things is that disability is a generic concept that covers many different ideas and programs. In our planning, we should strive not to become captured by any one image of disability or one picture of persons with disabilities. The population is large and varied. Rehabilitation planning needs to take this heterogeneity into account.

Finally, we need to remember that some trends are more enduring than others. Shifts between the public and the private sectors and between the state and the federal government have a cyclical quality. These cyclical shifts need to be differentiated from real points of discontinuity or from longer range shifts, such as the one from segregation to integration. That leads me to the conclusion that the rise of persons with disabilities as a group interested in its civil rights represents a more fundamental change than do the other things I have mentioned. Planning needs to recognize this change.

At the same time, even civil rights advocates need to understand the constraints that history imposes on planning. For all that times change, we continue to live with the legacy of the past in the form of contemporary programs. The field of rehabilitation offers few exceptions to this most basic of historical rules.

EXCERPTS OF REVIEWS AND COMMENTS

The following are excerpts of reviews, comments, questions and recommendations made by the Switzer Scholars. These are presented to further stimulate thinking, discussion and action as it relates to the contents of Chapter One by Edward O. Berkowitz.

The Berkowitz paper conjures up many sound philosophical and conceptual constructs. The focus on disability and the delineation of its many definitions and subsequent consequences for diverse groups (i.e., policy developers, trainer, educators, researchers, consumers of services and the "so-called" general public) is an issue that we should not underestimate during our discussions at the seminar.

It seems to me the distinctions between disability and handicapped need further development in order to provide, if attainable, a more realistic and universal acceptance on the part of the "non-professional." The implications of the Berkowitz paper have more of an impact on this group than any other allied group of professionals for one primary reason. All human beings have the potential to be "disabled" or "handicapped" at any given point in time, which is beyond control of the individual. We need to keep this perspective in mind when developing public information policy, training and research.

-- William A. Calzaretta

Edward Berkowitz has provided a succinct historical account of how the modern day rehabilitation program has acquired its major characteristics and, some would say, its excess baggage. In many respects his views are similar to Drs. Roth and Hahn who, in Chapters 3 and 4, also describe the difficulty that the traditional rehabilitation program has had in coping with movement to extend civil rights to people with disabilities. The traditional program has been institutionalized in state and federal government for decades and while it has undergone major changes and expansions in the scope of services provided and the populations of disabled persons served, it has not become a major agent advocating for the extension of civil rights to the disabled minority. It is essential that public policy-makers, professional rehabilitation leaders and disabled rights advocates collaborate on exploring whether there is legitimate and appropriate role for the traditional program in this civil rights movement.

A second issue which has confounded the intent of rehabilitation and income maintenance programs for disabled persons is the multiple meanings of the generic term "disability." Unintended policy consequences such as the creation of disincentives to employment have come about because differences among the various definitions and applications of the term "disability" have not been identified and reconciled at policy-making levels. This dilemma is still with us today as we freely use the terms "severe disability" and "severe handicap" interchangeably. In the current program initiative to expand transitional services to handicapped youth, rehabilitationists and special educators commonly use the term "severely handicapped youth" to

describe their target populations, yet each is referring to a decidely different populations with much different degrees of severe handicap. Dr. Berkowitz's observations on disability terminology should serve as a caution to policy-makers to attend to these definitional problems so that further unintended policy consequences are avoided.

Another note of caution which can be derived from Dr. Berkowitz' remarks is the **danger to the rehabilitation program** in over-relying on cost-benefit analyses to justify and market the program. Although the program's return on investment" to society has always been well received by legislators and other elected officials, the mere maintenance of positive cost-benefit data is not and has never been the purpose of the rehabilitation program. We must not lose sight of our basic mission and purposes as we weigh the trends in our socio-political environment and determine their implications for strategic planning in rehabilitation.

-- TERRY CONOUR

At the outset, I want to express my admiration and repsect for the research which Ed Berkowitz has conducted. At a time when few historians were apparently able to grasp the important contributions which a study of the history of disability policy can make to an understanding of contemporary issues, he has been a major pioneer. As other scholars follow the paths which he has blazed, there is little doubt in my mind that history will be aroused from its present status as a sleeping giant to offer many valuable insights about disability and the policy questions which its presents to the public and political leaders.

Nonetheless, I am compelled to state some criticisms of his analysis. Pershaps my major difficulty involved his definitions of disability. Berkowitz would have us believe that there are three distinct definitions. The first notion of damages collected as a result of injury or insult receives little subsequent attention in his paper which focuses on disability as a "state that lies between ill health and unemployment." In differentiating this condition from the third concept of "the handicapped," however, he seems to be making a somewhat specious distinction which may contribute to the **confusion** rather than the **clarification of disability policy.** This division appears to reflect a common tendency to treat disabled people as a "special" or separate category which does not even resemble others who are similarly situated. What this dichotomy fails to recognize is the extent to which persons who are unemployed for reasons obstensibly related to functional limitations partake of the characteristics of those whom Berkowitz labels "the handicapped." As a result of this conceptualization, the 55-year old with a bad back does not identify with the person in a wheelchair; and, perhaps most significantly, the political strength of both groups is consequently undermined. Instead of viewing disabilities as distinct entities or images, I consider it preferable to perceive disability as a continuum based on visibility and permanence which would clearly encompass the worker with a bad back as well as the individual in a wheelchair. This theoretical orientation at least permits an examination of the extent to which both persons become the victims of discrimination in an environment which is dominated by the nondisabled majority. Artificial classifications such as the ones presented in this paper seem to drain the concepts of prejudice and discrimination, as well as a common minority group membership, of intrinsic meaning.

Perhaps Berkowitz should not be faulted for this misconception because, as he points out, he is dsriving his conceptualization, as well as other notions such as cost-benefit calculations, have been bequeathed by historical legacies which did not regard people with disabilities as a minority group or understand their problems as a civil rights issue. As Berkowitz notes, "the rise of the handicapped as a group interested in its civil rights represents a more fundamental change than do the other things I have mentioned." The vast implications of this change have not been fully explored as yet. But there are crucial problems in his warning that "even civil rights advocates need to understand that (sic) constraints that history imposes on planning." History can be a liberating rather than a constraining experience. By founding his analysis on the definitions which have been inherited from the history of disability policy rather than on a disability as a generic phenomenon which has been treated differently in various historical eras, Berkowitz has neglected the important contributions which the minority-group definition can make to an understanding of history as well as other disciplines.

--HARLAN HAHN

The definitions of disability, at least in the first two cases, seem to be related to one's inability to work. They therefore appear to be work related. and have some implications for entitlement to benefits. There appears to be a different, and more positive, public policy response to these two groups. The third group, where definition rests on one's proof of disability, appears to cause the most difficulty in terms of consistency in public policy. It

may be that the more favorable public policy toward the first two groups stems from the ability of the general (nondisabled) population to identify with these two groups.

American public policy seem a little schizophrenic, -- disability is defined in terms of inability to work, yet expectations are that the disabled seek employment.

There is an historical evolution of disability policy. An early stage of outcast, a seond stage of care and isolation, a third stage of treatment and rehabilitation, and a current stage of rights and mainstreaming. This final stage may have overemphasized the expectation and focus on employment as the risk of other values and outcomes. Is it real, for example, to view vocational rehabilitation as the only alternative to income maintenance? It would seem that the pendulum has swung too far. the future may accommodate the concept of options and altenratives in which employment may or not be an important part.

Rehabilitation was also moved by the poverty programs and social consciousness of the 1960's. This reflected the first attempt by Vocational Rehabilitation (VR) to shift to serve welfare recipients, minority and special population groups, and contained a broadened definition of disability -- socially handicapped, functionally retarded, etc. This was also the era of "rapid action" services, high rehabilitation rates (26's), and a program that offered something for everyone.

Handicapped persons, even after the emphasis on service to severely disabled, clients rights, and consumer involvement, had never had substantial influence over the V.R. program at the operational level. Is not the tenacity with which the disabled hold onto the independent living (IL) program a statement not only of the relative importance of I.L. over V.R., but also because it represents an opportunity for control that they have not before had?

With regard to future trends, we must acknowledge that we are in a conservative environment (some have suggested backlash). There is at least some evidence that economics and traditional values may help shape public policy in the near term. This suggests a reexamination and potential moderation of such approaches as educational mainstreaming, deinstitutionalization, and competitive employment for all.

On a different level, if we examine the history of other minority groups, we can expect increased development and control by the disabled for the programs and social institutions which control their lives. In lesser degrees will others act for and speak for disabled persons?

-- L. ROBERT MC CONNELL

The notion that placing rehabilitation and disability in an historical context will help to isolate trends most relevant for the future is an important one. It is impossible to know first, where one is, and second, where one is going, without such an historical view. More importantly, an analysis of these issues is an important step in setting goals for the future and developing strategies to achieve those goals.

Berkowitz provides a state-of the-part-profession statement from a common and not extremely novel perspective. It is generally accepted that we are trapped by our history. It has brought us to where we are today, and we cannot change it in retrospect, even with the best of hindsights and intentions. He is right, too, in noting that policies are impacted by the definition of disability which is used. The three definitions he chooses, and on which the remainder of his paper are based, are ones with which I take issue.

The first definition of disability as "damages" is a misnomer. The justification for defining a personal injury in terms of the financial remuneration it engenders is not a component of "traditional rehabilitation philosophy." The second definition, that of disability as a state of unemployment produced by illness or injury, similarly is a misnomer. Disability and illness may result in unemployment, but the issue that we face in rehabilitation really is the cause (the disability) and what we can do to overcome it, rather than the outcome (unemployment) and what remuneration we can provide. The conceptual leap the author takes, that of stating that these two definitions involve an element of choice, comes across as somewhat biased. Berkowitz seems to be suggesting that persons choose to become ill or disabled in order to receive benefits. I cannot agree with this assumption.

The third definition, of disability as handicap, is closer to traditional viewpoints, but certainly not congruent with them. The disability creates a life situation for the individual which, in interaction with the environment, acts to create handicaps, but the two are not synonymous

Unfortunately the main text of Berkowitz's paper is predicated on the acceptance of these three definitions of disability. If one does not agree with the author's definitions, it is difficult, if not impossible, to accept much of the remainder of what follows.

--JANE E. MYERS

Dr. Berkowitz's observation about the difficulties we have in writing disability policy is clearly grounded in the historian's insight. History proceeds by fits and starts to produce the present. Disability policy is based on periodic reform, reactions to societal need, the emergence of strong leaders, and the like. So it is not surprising that the policy landscape is not tidy. The distinction between policies rooted in the damages that can be collected, the state between ill health and unemployment, and status as a special group labeled by society is useful to a point. It does allow meaningful discourse among disability analysts and, hopefully, with legislators and the public about issues that continue to bedevil the body politic.

To the extent that the Vocational Rehabilitation (VR) Program in the U.S. has shifted its program emphasis as a function of changes in the concept of disability over the years, that is good. It offers hope that the VR program can continue to adapt to new concepts and opportunities. As I see it, the VR program in the U.S. is struggling to make the next conceptual leap and connection to a rationale that permits broader public understanding and support.

To the extent that the VR program can fully embrace the independent living movement, to bring into the fold more severely disabled people whose needs will not be met by a "26 closure*," then it will remain a relevant program into the 1990s and beyond. The degree of resistance based on the "modern mania for professionalism" is what I worry about. Is it possible for professional schools to turn out professionals with values beyond "treating" patients or clients? Is it possible that professionals could identify with and serve the needs of disabled people for autonomy and self-determination? Or must professionalism be interpreted by professionals as requiring "control" over their practice and the subjects of their practice?

Dr. Berkowitz's view of future trends is intriguing. There is a suggestion that more experimentation with non-traditional forms of service organization will occur such as more involvement of the private sector. There is also suggestion that the entitlement to income maintenance will be stronger force than rehabilitation, that rehabilitation will no longer be viewed as the way to limit the growth of dependency on income transfer payments. If this is true, then the future of rehabilitation and disabled people is bleak indeed. American society has never given equal rights or opportunities to people who are seen as habituated to the public dole. The third trend toward using the civil rights movement and legal apparatus to push for "tickets into the labor force" is the one that I can most identify with. They might well seek concrete proposals for reinforcing the trend toward use of civil rights legislation to pursue more "tickets into the labor force" for disabled people. Secondarily, more tickets are needed into every other aspect of community living. My sense is that Americans will permit more access to broad community living opportunities on the basis of "ability to pay" than on any other basis.

-- JOHN H. NOBLE, JR.

** 26 closure is the designation of "Rehabilitated" by State Vocational Rehabilitation agencies.*

Those who understand history can be saved from repeating the mistakes of the past, but should that awareness be the sole guide in the establishment of public policy? Would not the utopian ideals of the great philosophers, ideals such as quality of life, freedom, and equal opportunity, serve better as the foundation upon which public policy is built?

One of the main points made by Dr. Berkowitz is that "policymakers ... do not operate at the level of images and metaphors. Instead, they work with the concrete structures created by distinctive programs. Disability policy, therefore, needs to be discussed at the program level." This is indeed a very pragmatic position; but is it not, in effect, like retrofitting society? By looking exlusively to program backgrounds for insights into change strategies, I fear we would limit creative solutions to the massive problems faced by persons with disabilities and perhaps, unconsciously, perpetuate medieval attitudes and methods.

To illustrate this point, I site the issue raised by Dr. Berkowitz concerning the distinction between income maintenance programs and vocational rehabilitation, and the failed attempts to blend them. He claims that there is now a trend to strengthen entitlements for the "pre-old" and to emphasize civil rights as a "ticket" to employment. His dismay at the disability rights movement's failure to see any contradiction between the trends may stem from the fact that he has the perspective of an **historian** and those in the movement have the perspective of **utopians.** One reason why the blend has not yet occurred may be because income maintenance programs are almost hopelessly ensnared in traditional concepts whereby disability means **inability to work**, and the receipt of entitlements is usaually an all or nothing situation with regard to "substantial gainful activity." If one could be rid of this tradition, it would not be so hard to imagine a system where disabled persons are reimbursed by the government for their disability-related expenses, whether or not they are working. A small step in this direction is the Sec-

tion 1619 demonstration project in the Social Security Administration which allows disabled persons receiving SSI to attempt or return to work and continue to receive Medicaid benefits. If allowed to succeed, this project has the potential to revolutionize the disability entitlement system.

Policy should be utopian, but implementation should be practical. An exemplary process which reflects this was used in the writing of the National Policy for Persons with Disabilities by the National Council on the Handicapped. Disabled persons, advocates, and service provides throughout the nation were personally asked what they would like to see in a national policy. Their input was used as the foundation for global statements in 18 areas of concern. This process demanded one type of creativity; the implementation process another. Bringing these concepts to a programmatic level will require the historical awareness described by Dr. Berkowitz. Just as the inventors of the "new math" began with a methodological ideal and had to cope with the public's attitudinal inertia in its implementation, so too will the proponents of the "new disabled person."

It is impossible to modify prejudice and misunderstanding. They must instead be replaced by equal opportunity and accurate perceptions. The new image of disability and the concepts of **quality of life** must be the root of policy. Programs grown out of eras of oppression and discrimination must overcome their past if they are to conform to the new reality.

-- **MARGARET A. NOSEK**

Dr. Berkowitz's paper presents a clear picture of a often murky situation. Viewing the historical evolution of disability programs enables the reader to better understand some of the modern conflicts.

This historical view also presents some certain challenges to the profession of Rehabilitation Counseling. It would seem that the optimistic foundations of the vocational rehabilitation program could be compatible with an enabling professional approach predicated on individual human rights.

The rights of individuals with disabilities could be enhanced by professionally trained rehabilitation counselors (RC) who took the role of counselor seriously. Professional RCs in this context would never be seen as "dominating persons with disabilities." Such domination would be contradicted by the "ethical" foundations of their profession. Also, they would not use diagnostic measures such as vocational and psychological tests to subjugate their clients as was hinted by Dr. Berkowitz. Such tests have always been a tool for counselor and client to explore relative strengths or relative interests, as anyone in the field would know.

The civil rights movement in disability is hopefully there to stay. As rehabilitation counselors trained during the rights-conscious times of the late sixties and early seventies enter policy-making positions, there will be a greater professional recognition of this movement.

In order to prevent premature obsolescence, the rehabilitation counseling profession needs to acknowledge a partnership with its consumers. Together with the community of persons with disabilities, the rehabilitation counseling profession strives for a world where the effects of disabilities are negated or minimized. The rehabilitation counselor is a highly trained professional who offers consumers alternatives for optimizing their interaction with their environment.

The key to the future of rehabilitation counseling when viewed form this historical context is H-O-P-E as described below:

Human Rights: Recognition and preservation of the human rights of persons with disabilities must occupy the foundation of the profession.

Optimism: The optimism of the twenties which accompanied the foundations of the vocational rehabilitation program must be retained as a cornerstone.

Professional Training: Professional preparation of rehabilitation counselors through C.O.R.E. accredited, RSA funded master's degree programs must be continued and improved. Ethical behavior andprofessional skills can be demanded from a professional not from a worker. Persons with disabilities have a right to and should expect professional treatment. One of the emerging characteristics of professions today is a partnership with consumers.

Enablement: Embedded in its early optimism was the concept that rehabilitation counseling could "enable" persons with disabilities to do things for themselves. It was seen as a vehicle by which persons might be trained for and acquired jobs. Today we can view rehabilitation counseling as an enabler which facilitates the road to greater independence and community participation for persons with disabilities.

-- **EDNA M. SZYMANSKI**

The author's historical perspective of society's evolving repsonse to its perceived needs of the disabled in the form of policy and related programs is invaluable. While the review underlines such problem areas so fundamental as definition of terms and clarity of concepts with resultant program

failures in addition to difficulties in reform, it also briefly redescribes an experience from which there is much to learn.

Society indeed has made major steps in its efforts to salvage the enormous human potential so long smothered under the blanket of various forms and degrees of disability. Giants like Mary Switzer in whose honor their seminar is dedicated, are to be remembered for their pioneering efforts in this area of human service.

In my opinion, however, we are just beginning, for there is much yet to be accomplished. The professionals of the various rehabilitation disciplines must reenforce their efforts toward the resolution of such issues as noted above. Additionally there is ample evidence suggesting that there are large numbers of disabled persons who never receive the opportunity for comprehensive rehabilitation services. They should be carefully identified and the reasons determined in order to close this service gap.

Further, the need for individualizing a proper matching of rehabilitation services and/or income maintenance for specific persons must be more widely acknowledged, and provided within the context of the dynamics of a disability and its determinants as they change over time. In so many instances, it is not an "either/or" need but an appropriate balance of each. This concept should include tax abatement for certain employed persons with impairments. It would also seem that the rapid advances in the high technology and information industries can be used to facilitate greatly needed research, and similarly, program development -- changes which should follow.

Key to this whole process I believe, can be the developing self-advocacy and informed professional advocacy activities which can catalyze the continuing positive evolution of the rehabilitation concept, and its translation into imaginative policies and effective programs.

-- HERBERT THORNHILL

Dr. Berkowitz's opening statement, "seminars of this type provide room for speculation," very aptly describes my reaction to many of the issues raised in his presentation of the historical perspective of rehabilitation and its implication for future planning.

I agree that disability from an operational standpoint has evolved as a heterogenous concept. However, it has done so in direct relation to the "raison d'etre" of particular or specific programs and their stated objectives. More often than not, the decision is made to provide some type of a service or benefit to a segment of the population, and the procedures for doing thus, **and the development of the definitions** are driven by certain political agendum, and in many cases **perceived** but not necessarily **real** programmatic and fiscal constraints.

I concur that to elect maintenance of the "20's" model of vocational rehabilitation will not result in persons with disabilities reaching any appreciable level of economic or social parity. I am reminded of a "model" very prevalent in the 1960's and early 1970's; that of the "systems approach to management." How do programs emerge? And, why do they so often appear in operation to have no discernible connection with the stated goal? Although I hesitate, as does Dr. Berkowitz, to make generalizations, in my opinion many of these programs appear so due to a failure to work "backwards" in the development of their methodologies. One doesn't decide to construct a lamp, and from that point go directly to the purchasing of the materials. Once the decision is made that a lamp is needed to provide light, the determination must then be made as to how much illumination is required (or desired); what aesthetic characteristics are preferred; the requisite dimensional measurements; etc. Otherwise you end up with a bulb whose wattage capacity is insufficient; wiring designed to accommodate an outdoor display; and a shade too small for the base. The resultant affect is a constant redesigning and restructuring of specific elements, one at a time. In the meantime, the original goal remains unmet. Many programs operate in this fashion ... heterogeneity emerges due in part to this phenomenon.

In reference to the statement in the paper that one of the differences in each of the three definitions of disability outlined by Dr. Berkowitz is the element of choice; I see no element of choice implied. The manner or place in time that a disabling condition arises occurs without option of the individual.

I strongly feel that perpetuation and acceptance of the concept that "all programs have limits and have difficulty in stepping outside of their historical identities," however true, will continue to result in development of a universal disability policy remaining an idealistic pipedream. Past may be prologue to the future , but does not necessarily have to be ultimate designer. Although many of Dr. Berkowitz's historical observations appear to me to be contradictory when applied to the task of speculating future policy development. I agree one hundred percent that the rise of persons with disabilities as a group interested in its civil rights represents a more than fundamental change.

-- JANICE A. WOODWARD

Summary of Recommendations

The following is a summary of the recommendations and implications for action developed by the Switzer Scholars as they relate to the topics of Chapters One, Three and Four. (The Recorder was Richard P. Melia)

1. Recommendations/implications that would enhance service delivery:

The group noted that the vocational rehabilitation program is one of the oldest human service programs within the Federal-State system. Chapter One by Berkowitz notes that the program has been transformed several times in its 65 years of existence. The emergence of a "politics of disability" with significant groups of disabled people speaking out for their needs is creating new reasons for rehabilitation to again be transformed or renewed. Therefore, the primary recommendation to enhance delivery is to:

"Redo Rehab" and "Renew Rehab" so that the services system meets individuals' needs. Vocational Rehabilitation, and all programs serving disabled people, have a responsibility to look closely at the organization of their services, at their bureaucracies, and ensure that programs reflect consumer concerns and needs.

2. Recommendations/implications for policy or program development:

Examine newly emerging approaches such as **transitional and supported employment** as innovations which provide direct services while also introducing new organizational settings and less bureaucratic services. These methods may have additional advantages of being more sensitive to individual needs.

Provide more diversification in job-placement in Vocational Rehabilitation (VR) through alternatives to current approaches. One possible action step which might reduce bureaucracy while improving access of consumers to services and enriching resources would be to co-locate VR placement and independent living services.

3. Recommendations/implications for training of staff and the general public:

Training is a crucial lever for program improvements sensitive to individual's needs. Innovations such as those noted under #1 and #2 above should always be accompanied by adequate and ongoing training efforts which include a significant role for the consumers of the services interacting with the providers of the services.

4. Recommendations/implications for needed research:

Professionalism should not separate the provider from the consumer. Rather, its essence consists of the capacity to serve consumers and reform society in collaboration with them.

This brings to mind a statement by Frederick Kappel, former Chairman of the Board, American Telephone and Telegraph Corporation:

Research is wonderful and fascinating because it turns up new knowledge that leads to new products and ... to new and improved services; but it is just as wonderful in the way it keeps upsetting people who want to follow traditional paths.

Research is born out of dissatisfaction with what we already know and are already doing, and in turn, the new knowledge it brings us requires that we continaully reexamine and change existing ways."

A major implication of rehabilitation research is that it can be upsetting to both consumers and rehabilitation professionals. The professional and the consumer are in the same boat. There is a constant need for consumers' groups to meet with professional groups at all level to investigate and act upon concerns that influence both. Several barriers must be overcome for such exchanges to be most effective in reexaming and changing existing ways of providing rehabilitation services.:

- *consumers do not get the "full picture" of the agency's environment, choices which must be made, and methods of organizing services; the same point is often true of first-line professionals;*
- *many programs (and professionals) organize their business so as to keep the consumer at a distance and clearly differentiated as a "client" or "patient;"*

5. Recommendations/implications for legislation -- Federal, State, Local:

Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) should **not** use the same definitions of disability for eligibility.

SSI is a safety net program for persons who have not had significant experience in the labor force. A person with a substantial impairment who has not worked often requires significant assistance to

enter the work force. Many such individuals require ongoing support to remain employed and would benefit from programs of **transitional** and **supported employment** which emphasize learning the job at the actual job site. In the years to come SSI reform will have major implications for persons emerging from educational programs as well as for persons from institutions or extended day activity programs. In order for public policy to be responsive to the needs and circumstances of people who have never participated in the labor force, definitions of that population require elaboration in ways which differ from the SSDI (or labor force experienced) population. Public policy discussions should focus on what these differences are, how they impact upon individuals and families, and how public policies can best address them.

Legislation, as it addresses important issues such as these definitions, must reflect needs of consumers as well as providers. Since providers and organizations have far greater resources than consumers for influencing the formative stages of legislation, more needs to be done to involve consumers in the legislative process. Examples such as congressional committees, and organizations advising the congress such as the National Council on the Handicapped, holding hearings in various regions of the country offer methods of making the legislative process more accessible to disabled consumers.

6. Recommendations for any area not categorized in above listing:

There is a need for incentives for professionals in rehabilitation to become involved in the "minority group model" approach to viewing and responding to needs of disabled persons. Rehabilitation workers often receive all of their "rewards" for performance based upon "clinical" or "bureaucratic" indicators of performance. There is a need for **new performance meausures** which would recognize accomplishments which reduce or eliminate service barriers, which enhance the status of disabled people as individuals deserving of rights and respect from society. Possible innovations in services to reduce bureaucratic barriers which might be an incentive for some direct service workers include:

- *making communication with families, employers, and disabled people in training settings an expected part of the job for direct service workers in rehabilitation;*
- *encouraging counselors to visit places where disabled persons are working and learn their jobs, progress;*
- *facilitating counselor contact with "past clients;"*
- *opening new avenues of communication for rehabilitation counselors and other professionals to interact and provide services in "non-traditional ways" (eg. relaxed dress code, flexible location for "office hours", permitting direct assistance at job sites during initial days of employment, etc.).*

REMEMBERING MARY SWITZER: Paul Howard (far left), Special Consultant to the White House and a former aide of Miss Switzer, recalls Mary's vast accomplishments for a willing audience of Switzer admirers. Listers are, left to right, Harry Sands, Post-Graduate Center for Mental Health and a former Seminar host; Dr. James H. Semans, 1984 Scholar; and Dr. Leonard G. Perlman.

Scenes

PRESENTATION: Edwin Martin (center), HRC, surprised Dick Switzer with a bronze bust of his famous aunt, Mary. Ruth Velleman (left), head librarian at HRC, participated in the presentation.

PCEH'S SCHOLAR: Above, Bernie Posner, Executive Director of PCEH presents the Switzer Scholar Award to staffer Antonio Suazo, a 1984 Scholar. Below, storyteller Dr. Phyliss Ruebenfeld (left), President of ACCD. delights Scholar Anna Fay (center) and Dr. Leonard Perlman, Seminar Coordinator.

Switzer Scholar Haber

Chapter Two

*Trends and Demographic Studies on Programs For Disabled Persons**

By Lawrence D. Haber

In 1975, I presented a paper on "Disability Definitions: Implications for Programs and Policy Development" at the First Mary Switzer Memorial Seminar in Cleveland. At that time I reviewed the general concepts of disability, examined the distinctions between disability, impairments and functional limitations and discussed the implications of differences in disability criteria for the programs in which these disability definitions are used.

In my paper for the Ninth Switzer Seminar I would like to review the changes which have taken place in some of these major programs over the intervening period, look at some recent developments in disability definitions and examine the state of our knowledge or understanding of the level of disability prevalence in the population.

The first subject, programmatic developments, can be disposed of relatively quickly. Although there has been activity in these programs, there is little information available on the progress or effects of the programs.

Section 504 of the Rehabilitation Act of 1973 has become accepted as the "Civil Rights Act for the Disabled Persons." There seems to be little question that it has institutionalized a sense of entitlement for the disabled persons among the general population and in the federal government and has been a stimulant towards the organization of disability advocacy groups. Since there is no program core for this legislation, it is difficult to say what effect this has had directly in providing more opportunity, more employment, or other concrete benefits as against conceptual benefits for disabled persons. This is not to disparage the effects of Section 504, but simply to point out that there is little or no information on the concrete benefits or effects of the legislation, aside from the substantial body of regulations and technical assistance developed by the federal departments and program agencies. More than 30 agencies have completed the regulations required by the 1974 amendments. Over 90 agencies are now working on the regulations required by the 1978 Executive Order extending Section 504 to federal government activities. Unquestionably, Section 504 has had an impact on the consciousness of the nation.

I am not aware of any studies which have attempted to use the statutory definition as a basis for identifying or defining disabled persons included under this definition. Given the amorphous nature of clauses (b) and (c) of the statutory definition, it would be difficult to apply the statutory definitions literally.

In 1975 one of the major concerns of the Social Security Disability Insurance program was the trend to the level of disability applications which had been increasing over a period of several years. In 1976 disability applicants reached their high point of approximately 1.3 million applications and have since declined to a level of about one million applications a year. There have been no major changes in the disability entitlement provisions or definitions. The major problem in recent years has been the disability beneficiary review in which several hundred thousand people were taken off the disability rolls, with most of them being subsequently reinstated. The most recent Social Security legislation (1984) was intended to limit the extent to which the review pro-

cess can be used to make such wholesale determinations in the future.

Although many changes have been taking place in the administration of vocational rehabilitation services, the definitions have not changed significantly since 1975 and may, for most purposes, be considered as substantially the same.

There has, however, been a substantial and significant change in disability provisions for the education for handicapped children, under PL 94-142. Since 1977 the finding for the program in constant dollars has increased two and one-half fold, from approximately $415 million to $1,018 million. The expenditure per child has increased from approximately $119 to $251. Although there are differences of opinion as to how well the program is carrying out its objectives of mainstreaming handicapped children and the extent to which the federal government is paying its share of the program which it has largely fostered, there is little question that education for handicapped children has been institutionalized within the school system. The most recent legislation (PL 98-199) is directed towards expansion of the program into the transitional problems of post-secondary education and work entry and to remedies for architectural barriers. Within the elementary school program, the major trend has been towards increased services for children with learning disabilities, now estimated at about four percent of the enrollment and a decrease in the proportion of children identified under "physical and other handicapped conditions."

Definitions of the Disabled and the Handicapped

The major new addition to the literature on disability definitions has been the experimental work of the World Health Organization (WHO) in their "international Classification of Disabilities and Handicaps." WHO is to be applauded for the exhaustive way in which they have approached the definition of disability. Their attempts at classifying types of impairments, disabilities, and handicaps suggest a number of areas for further study and examination. At the same time, I must expresss my own reservations about the extent to which the WHO approach has confused the distinctions between **impairment, functional limitations** and **disability** and the extent to which the distinctions between disability and handicaps attempted in the WHO classifications detract from rather than contribute to the clarity of the distinctions being drawn.

In my own review of the WHO classifications, I have great difficulty distinguishing between the use of disability, as a "personal or individual" variable, and as an environmental or systems factor, in the references to "handicaps." The report does not clarify my understanding of what factors are taken into consideration, how they are identified, or how they are measured. While the attempt to develop or clarify a level of distinction between the two is laudable, I do not feel it has been successful.

The distinctions, which have been widely used in research at the Bureau of the Census, the National Center for Health Statistics, and the Social Security Administration, rely more heavily on the generally accepted distinctions between **chronic conditions,** as the state of active pathology, **impairments,** as physiological, anatomical or mental loss or abnormality, **functional limitations,** as the restrictions in physicial and communications abilities resulting from these impairments and **disability** as the loss or limitations of ability to perform socially expected or prescribed tasks and roles within a social environment.

The WHO concept of disabilities, however, seems to partake of both the impairment concept and to overlap with the handicapped concept. Rather than being a clarifying intermediary it is, in my view, a confusing one. The different treatment or interpretation placed on terms such as "disabilities" within the rehabilitation environment, incomparison to the medical guides for income maintenance and income replacement programs, has already caused enough confusion without further compounding this with another restatement of the meaning of disability which seems to partake at times of neither and at other times of both handicaps and impairments.

In terms of its application to demographic studies of the disabled population, our analysis indicates that the WHO classification scheme for handicaps does not provide a useful approach to the classification of survey data. We have difficulty in differentiating between economic deprivation due to factors of impairment or disability and economic depreciation due to other social and political factors. The overlaps between intellectual and psychological impairments versus behavior disabilities, in comparison to orientation handicaps, are not clear. It is doubtful that these distinctions can be measured in a survey interview. The distinctions between family **occupation disabilities** and **occupational handicaps** are not clear. Similar questions could be raised about the communications disabilities, in comparison with communications impairments, personal care disabilities, in comparison with physical independence handicaps and locomotive disabilities versus mobility handicaps.

Many of these statements seem to offer distinctions without differences. The generality of the "occupational handicapped" category is not specific to the different social tasks and roles of the aged and the young. The specifications of frequency of occupation or activity are unclear, difficult to measure and are of doubtful value in comparison with the occupational employment and other activity classifications now generally in use. Without belaboring the point too extensively, my general reaction is that the report may deserve further study for possible improvements in the definitions but that the basic distinctions between disability, handicaps, and impairments are blurred and that the WHO classification scheme creates more problems than it solves.

It is also interesting that the WHO classification manual contains no references to the research conducted in the United States in the '60s and '70s, prior to the initial release of the WHO manual in 1976 and its publication in 1980 (including the papers presented at the 1975 Switzer Seminar). Possibly a more extensive examination of this body of research and literature would have avoided the ambiguity and the overspecificaiton of the WHO classification approach.

Since I have no experience in individual case finding and classification for treatment and service purposes, I am not in a position to make any assessment of the value of the WHO classification system for rehabilitation and counseling services. It is doutbful that the WHO classification system can be applied or adopted to survey research and demographic surveys in a meaningful or reliable way. It would be interesting to hear from the rehabilitation professionals who use case finding and case management techniques for purposes of treatment and service what their experience with this classification system has been.

Disability Surveys: Recent and Ongoing Research

Several large-scale demographic studies have been conducted in the past nine years which have provided us with a substantial array of data on persons with disabilities: the 1975 Survey of Income and Education (SIE); the 1978 Social Security Survey of Disability and Work, the 1980 Census Disability Questions, the continuing National Health Interview Survey conducted by the National Center for Health Statistics and the 1979-80 Home Care Supplement, the 1977 Disability Supplement, and the 1981 Child Health Supplement. The 1980 census had questions on work limitations, similar to those asked in the Social Security and the National Center for Health Satistics Surveys. Disability identification questions have been added to the March Supplement for the Current Population Survey. The new Survey of Income and Program Participation asks about current disability and disability income in the core questionnaire and includes a health and disability supplement in one wave of each two-year panel, with a possible followup for longitudinal comparisons.

In general, these studies show a similar demographic and economic composition of the disability population as was found in the earlier surveys. Persons with disabilities are disproportionately older, less educated, and less occupationally skilled than nondisabled persons. Disability appears to strike more heavily among older persons, among Blacks than Whites, among the semi-skilled and unskilled than among skilled and white-collar workers, and among those with less education than among those with more education. Disability problem rates are highest in the South and in rural areas. Farmers also constitute a higher proportion of the disability population and of those with severe disabilities. Economically, of course, disability persons have considerably less income than nondisabled persons and are more likely to have incomes at or below the poverty levels. They are less likely to be employed or to be employed full-time. Of those who are employed, their incomes and earnings tend to be lower than those of nondisabled persons.

The 1972 and 1978 Social Security Studies found that the distribution of chronic disease among the disability population was similar to that among the population in general. Among the disabled persons, as among the nondisabled persons, musculoskeletal disorders and cardiovascular diseases were the most frequently reported major disabling conditions. About four-fifths of the disabled population reported one or more limitations in physical activity but only about one in eight reported a limitation in mobility activities: needing help for transportation or to get around outside of their homes. Among those with severe disabilities, about nine out of ten reported a limitation in one or more physical activities and one-fifth reported a need in assistance for mobility activities. Close to half of the respondents with severe disabilities reported a severe loss of functional capacity as compared to slightly more than one-tenth of those with occupational and secondary work limitations.

Although the social and economic composition of the disabled population has shown a high degree of consistency over the years and over a variety of studies, the overall level of disability prevalance has varied quite considerably among these studies. This is best shown by a comparison of the major population surveys with disability prevalence estimates.

Table 1
Prevalence of Work Disability: Selected Surveys, 1966 to 1982

Survey	Both sexes: percent-				Males: percent-				Females: percent-			
	With a work disability	With a severe work disability	Prevented from working	Of work disabled persons in the labor force	With a work disability	With a severe work disability	Prevented from working	Of work disabled persons in the labor force	With a work disability	With a severe work disability	Prevented from working	Of work disabled persons in the labor force
1966 SSA[1].....	17.2	5.9	NA	52.1	17.2	4.7	NA	73.7	17.2	7.0	NA	32.6
1967 SEO[2].....	14.0	NA	5.2	NA	14.0	NA	NA	NA	14.0	NA	NA	NA
1969-70 HIS[3,5]...	11.9	NA	2.2	NA	13.1	NA	3.5	NA	10.9	NA	1.0	NA
1970 Census[3]....	9.4	NA	3.8	46.2	10.2	NA	3.2	63.4	8.6	NA	4.4	27.3
1972 SSA[4].....	14.3	7.0	NA	47.9	13.6	5.7	NA	65.1	15.0	8.3	NA	33.8
1976 SIE[1].....	13.3	NA	5.8	43.7	13.3	NA	5.1	57.0	13.3	NA	6.4	31.2
1978 SSA[1].....	17.2	8.6	5.8*	44.2	16.1	7.5	5.1*	59.7	18.4	10.0	6.6*	30.8
1980 Census[3]....	8.5	NA	4.4	38.1	9.0	NA	4.0	49.1	8.0	NA	4.7	26.3
1980 HIS[3,5].....	13.5	NA	2.8	NA	14.3	NA	4.7	NA	12.8	NA	1.1	NA
March '81 CPS[3]	9.0	NA	NA	33.0	9.5	NA	NA	41.8	8.5	NA	NA	23.5
March '82 CPS[3]	8.9	NA	NA	32.8	9.3	NA	NA	41.5	8.5	NA	NA	23.7

[1]Universe comprised of noninstitutional persons 18 to 64 years of age.
[2]Universe comprised of noninstitutional persons 17 to 64 years of age.
[3]Universe comprised of noninstitutional persons 16 to 64 years of lage.
[4]Universe comprised of noninstitutional persons 20 to 64 years of age.
[5]HIS activity limitation data refer to "main activity" which is considered to be keeping house for women not currently working.
*Estimate based on unpublished data provided by SSA.

Table 1 shows the disability prevalence rates for 11 studies, including the 1970 and 1980 Population Censuses. These studies range from a high of 17 percent, in the 1966 and the 1978 SSA surveys to a low of 18.5 percent in the 1980 census. Studies with low estimates of disability include the 1970 and 1980 censuses and the 1981 and 1982 CPS March Supplement, all of which are closely grouped around nine percent. Studies with intermediate levels of disability prevalence include the 1967 SEO*, 1972 SSA*, 1976 SIE*, and the 1969-70 and 1980 HIS* surveys.

It is apparent that the differences do not represent a long term or secular trend. Year of study show little or no relationship to disability rate. The purpose or focus of the study appears to have the greatest effect on the estimate of prevalence. The studies with the lowest estimates (CPS and the decennial census) are general purpose studies with little emphasis on disability. The SSA studies, with a strong focus on disability, produce the hightest estimates of prevalence.

The large variations in disability prevalence levels among the studies have raised questions about the reliability and validity of the measurements of disability used in these surveys. Examination of the detailed data, and comparisons among data sets, however, suggest a reasonably high degree of consistency in the distribution and composition of the disabled population. The relationship of disability to major social and economic variables, such as age, sex, labor force participation, income, race, marital state, and other variables has been highly consistent across surveys.

These finding pose difficult questions. Why do disability prevalance levels vary substantially from survey to survey while the internal distributions remain consistent across surveys? What factors in the survey methodology and interview environment cause the sizeable differences in the percent of the population disabled without affecting the composition of the group identified as disabled? What can be done to reduce this variation, to improve the reliability of measurement or to at least explain the intervening factors so that we may adjust or understand the findings from surveys done under different conditions?

The questions are of more than purely or methodological interest; they have a bearing on policy issues for several federal programs which disburse billions of federal dollars. Regardless of which measures are used, disability affects a sizeable fraction of the adult population. disability is a major reason for leaving the labor force and for early

retirement; it is a significant factor in the level of poverty found among working-age adults, blacks, older workers, the less educated and those with unskilled and semi-skilled occupational backgrounds.

Surveys which produce high estimates of prevalence may do so by identifying as disabled larger numbers of persons who have relatively minor limitations. If this is the case, one would expect to find a positive relationship between the disability rate and the proportion of disabled persons who are in the labor force. Table 1 shows little evidence of such a relationship. For example, the 1972 SSA survey produced a much higher estimate of prevalence than the 1970 census, but both studies showed about the same figures for percent of disabled persons in the labor force.

The percent with a severe disability shows substantially more stability over various studies than the total disability rate. The three SSA studies show a trend in estimates of the percentage of persons with severe disabilities from 5.9 percent in 1966 and 7.0 percent in 1972 to 8.6 perecent in 1978. The 1980 census estimated that 4.4 percent of the population was prevented from working compared to 3.8 in 1970. The SSA category of "severe disability" includes persons who are unable to work regularly, as well as those who are unable to work at all. When the same criteria are used, the difference between the census results and the SSA results becomes less pronounced. The 1978 SSA estimate of the percent not in the labor force and unable to work, 5.8 percent, is fairly close to the 1980 census estimate of 4.4 percent.

The HIS data present special problems of interpretations. Until recently, women who were not currently working were asked "housework" disability questions rather than "work" disability questions. Examining the HIS figures for men only, the 1980 HIS shows that 4.7 percent were unable to perform their major activity (work). That figure is quite close to the census and SSA estimates of 4.4 and 5.8 percent.

That figures cited above suggest that most of the variation and inconsistency in disability estimates are attributable to prevalence estimates of the less severe disabilities rather than estimates of severe disabilities. This conclusion is consistent with the results of early SSA methodological studies which examined alternative disability survey screening procedures (Haber, 1967) and with recent data from the labor force studies (McNeil, 1983).

The differences in language and concept between terms such as the "severely disabled," "unable to work" and "prevented from working" illustrate some of the difficulties in comparing disability estimates across surveys. Differences in the defined universe shown in the footnotes on the age specifications in Table 1 illustrate another problem. These, however, are overt and intentional differences in definition, which can be measured or accounted for. Other factors related to specific wording, placement of questions, training, and context are more subtle and less obvious in their consequences.

The concern with variation in disability prevalence estimates assumes that we are measuring or attempting to measure the same behavior. While this is the intent of all of these studies, there are, in fact, a number of differences in methods, purpose, or context of the study. Some of these appear to be fairly minor. However, the assumption that they are minor is speculation on our part. We really have little basis, in fact, for assessing the effects of differences in working, question placement, survey focus and interviewer training on the level of disability reported.

Table 2

Compariaon of disability Identification Questions: Selected Studies, 1966-1982

1966, 1972, and 1978 SSA

1 Does your health or condition limit the kind of amount of work you can do?

2 Does your health or condition keep you from working altogether?

3 Are you now able to do the same kind of work you did before your work limitation began?

4 Are you now able to work full time or can you work only part time?

5 Are you now able to work regularly or can you only work occasionally or irregularly?

The classification scheme included the following categories of work disability status:

Severe. Unable to work altogether or unable to work regularly.

Occupational. Able to work regularly but unable to do some work as before onset of limitation or unable to work full time.

Secondary. Limited to the kind or amount of work that can be done, but able to work regularly at a full time job and able to do same work as before.

1967 SEO

1 Does ... 's health -
A. Limit the kind of work ... can do?
B. Limit the amount of work ... can do?
C. Keep ... from working?

2 How long has ... been limited in this way?

1970 Census

1 Does this person have a health or physical condition which limits the kind or amount of work he can do at a job?

2 Does his health or physical condition keep him from holding any job at all?

3 How long has he been limited in his ability to work?

1976 SIE

1 Does ... 's health condition--physical, emotional or mental--limit the kind or amount of work ... can do?

2 Does..'s health keep..from working at a job at all?

1980 Census

Does this person have a physical, mental, or other health condition which has lasted for six or more months and which

1 Limits the kind or amount of work this person can do at a job?

2 Prevents this person from working at a job?

NHIS (1980 and earlier years)

19a What was ... doing most of the past 12 months (for males): working or doing something else
(for females): keeping house, working or doing something else?

b What was ... doing?

If 45 years and was not "working" "keeping house," or "going to school," ask:

c Is ... retired?

d. If "retired," ask: Did he retire because of his health?

23a Does ... health now keep him from working?

b Is he limited to the kind of work he could do because of his health?

c Is he limited in the amount of work he could do because of his health?

d Is he limited to the kind or amount of other activities because of his health?

24a Does ... NOW have a job?

b In terms of health, is ... NOW able to (work-keep house) at all?

c Is he limited in the kind of (work-housework) he can do because of his health?

d Is he limited to the amount of (work-housework) he can do because of his health?

e Is he limited in the kind or amount of other activities because of his health?

1981 and 1982 CPS, March Income Supplement

59a Does anyone in this household have a health problem or disability which prevents them from working or which limits the kind or amount of work they can do?
Yes No (skip to 60a)

59b Who is that? *(Anyone else?)*

60a Is there anyone in the household who has a service-connected disability or who ever retired or left a job for health reasons.?
Yes No (skip to 61a)

60b Who is that (Anyone else?)

Persons were classified as having a work disability if they were identified as having a work disability in either of the direct items or if they met any of the following criteria:

1 Did not work in previous week because has long term physical or mental illness or disability which prevents the performance of any kind of work (based on response to "main activity last week" question on the basis CPS questionnaire).

2 Did not work at all in previous year because ill or disabled (based on response to "reason did not work last year" question on the March Supplement).

3 Under 65 years of age and covered by Medicare.

4. Under 65 years of age and a recipient of Supplemental Security Income.

Of the 13.1 million persons between the ages of 16 and 64 years who were classified as having a work disability, about 10.4 million were identified by the first direct item as having a work disability. The second direct item identified an additional 1.2 million persons. Approximately 1.5 million were not identified as disabled by either of the direct items but were identified as disabled by one or more of the indirect items.

Table 2 compares the wording of the questions for the studies shown in Table 1. The four SSA studies use identical language, the 1967 SEO and 1976 SIE are fairly similar. The HIS questions screen on "usual activities" in the past 12 months. Otherwise, the basic questions are similar. The "usual activities" screen reduces disability reporting for women whose "usual activity" was keeping house, but should not effect reporting by men. Different questions referring to the same behavior or attributes were used in the 1970 and 1980 censuses. The CPS March Supplement disability identification is derived from several questions tied into the income and employment sections of the questionnaire.

The data on reliability of the data also show variations from study to study. However, comparison of the disability rates for states, from the 1970 census, the 1976 Survey of Income and Education (SIE), and the 1980 census shown a high rate of consistency among state disability rates (Table 3). The correlaton coefficient between the two sets of state estimates is 0.89 for the 1970-76 and 1970-80 comparisons and 0.93 for the 1976-80 comparison. Comparisons of the state estimates for "complete work disability" found correlation coefficients between 0.93 to 0.95 for the three periods.

Indices of inconsistency available for five studies conducted between .21 and .53 (Table 4). Two of the higher indices were found in the two panels of the 1976 National Content Test. The questions in the National Content Test were complex and a major departure from previous identification methods. Based on examination of these data, the complex questions were discarded and a simpler set of questions was used in the 1978 Richmond Census and the 1980 census. These questions were closer to

Table 3
Indexes of Inconsistency for Work and Other Selected Characteristics: Based on Reinterview and Matched Studies

Item	Characteristics	Index of inconsistency	Name of Study
1.	With a work disability	53	1970 Census vs 1972 Survey of Health and Work Characteristics (matched study)
2.	With a work disability	41	1976 National Content Test: Panel I vs Reinterview
3.	With a work disability	38	1976 National Content Test: Panel II vs Reinterview
4.	With a work disability	26	1978 Social Security Administration Disability Survey vs Reinterview
5.	With a work disability	21	1980 Census Disability Survey Pretest vs Reinterview
6.	With a work disability	53	1980 Census Disability Survey Pretest vs 1978 Census Pretest (matched study)
7.	Covered by Medicaid	27	1976 Survey of Income and Education vs Reinterview
8.	Unemployed	32	1980 Current Population Surveys (January-June) vs Reinterview
9.	Not in the labor force	40	1980 Current Population Surveys (January-June) vs Reinterview
10.	Divorced	24	1970 Census vs March 1970 Current Population Survey (matched study)
11.	Highest goals completed was 4 years of High School	26	1970 Census vs March 1970 Current Population Survey (matched study)
12.	Major occupation group was managers and administrators	39	1970 Census vs March 1970 Current Population Surveys (matched study)
13.	In poverty in 1969	40	1970 Census vs March 1970 Current Population Survey (matched study)

those extensively tested by the SSA and used in earlier studies.

As shown in Table 4, the Index of Inconsistency for the disability estimates from the 1978 Census Survey Pretest was in the same range as the 1978 SSA Disability Survey, .21 and .26 respectively. The inconsistency levels found in these studies compare favorably with those of a number of other items whose reliability is widely accepted, for example, the percent of the population divorced, completing high school, or not in the labor force.

Our review of the recent research on disability prevalence shows (1) a high degree of variation among estimates, (2) a reasonable level of reliability, at about the same level as other variables commonly used in social statistics, and (3) a basic consistency of relationship to major social and economic characteristics. The data are widely used and a definite need exists for reliable and consistent data on disability.

The wide variation in disability estimates, however, poses problems for researchers and policy and program users of disability statistics. Which level of disability prevalence is correct or appropriate for a particular purpose? It is difficult to explain or to justify glaring discrepancies between estimates such as the 1978 SSA disability rates (17.2 percent), the 1980 HIS rates (13.5), and the 1980 census (8.5 percent).

In order to develop the best methodology for

future surveys, a program of research and evaluation is needed to provide a better understanding of the factors which affect the disability response levels. Although some work has been done in this area, a more organized and systematic approach is needed than has been undertaken to date.

Content Reinterview Survey

Data from the Census Content Reinterview Survey may provide us with some of the insights needed to improve measurements in this field. This study compared responses to the 1980 census disability questions with those from the more intensive reinterview survey, conducted about eight to 10 months later (November 1980-January 1981) using cases matched to the census records.

The data we have just started to receive data from the Content Reinterview Survey show a relatively high degree of agreement between the census and the Reinterview responses. There is also a systematic net difference of about three percent with higher estimates reported in the reinterview survey (CRS), as shown in Tables 5-7. This suggests that more information input into the interview and more specificity on limitations content increases the respondent's tendency to report a work limitation.

Table 7 compares prevalence rates and response consistency among people with and without physical movement limitations. We, of course, expect the prevalence to be very different for those two groups. The differences in response consistency is, however, very striking and suggestive.

Table 4

Percent of Persons With a Work Disability as Measured in the 1970 Census, 1976 SIE and 1980 Census

Divisions, regions, and states	1970 Census: Percent of persons aged 16 to 64 with		1976 SIE: Percent of persons aged 18 to 64 with		1980 Census: Percent of persons aged 16 to 64 with	
	a partial or complete work disability	a complete work disability	a partial or complete work disability	a complete work disability	a partial or complete work disability	a complete work disability
UNITED STATES, total	11.2	4.3	13.3	5.8	8.5	4.4
NORTHEAST						
New England:						
Maine	11.2	4.3	13.7	5.6	9.7	5.0
New Hampshire	9.3	3.1	11.3	4.1	7.5	3.3
Vermont	12.4	4.2	13.0	5.3	8.5	4.1
Massachusetts	9.9	3.4	10.8	4.4	7.3	3.6
Rhode Island	10.1	3.7	12.9	5.3	8.6	4.5
Connecticut	8.7	2.5	10.5	3.9	6.5	2.9
Middle Atlantic:						
New York	9.7	3.9	11.1	5.7	7.7	4.4
New Jersey	9.2	3.1	11.7	4.8	6.9	3.6
Pennsylvania	10.5	4.2	12.9	5.8	8.5	4.7
NORTH CENTRAL						
East North Central:						
Ohio	10.9	4.0	13.6	5.9	8.8	4.6
Indiana	10.5	3.5	12.3	4.9	8.0	3.7
Illinois	10.2	3.6	12.2	5.2	9.3	4.6
Michigan	11.5	4.0	13.2	6.1	9.3	4.6
Wisconsin	9.7	2.8	11.6	3.7	6.8	2.9
West North Central:						
Minnesota	10.2	2.9	12.1	4.0	7.0	2.6
Iowa	10.7	3.2	11.1	3.9	7.2	3.0
Missouri	12.0	4.7	13.8	6.1	9.1	4.6
North Dakota	9.9	3.2	11.3	3.5	6.7	2.5
South Dakota	10.7	3.2	11.9	3.6	7.6	2.9
Nebraska	10.5	3.0	9.7	3.0	7.0	2.7
Kansas	10.7	3.4	11.7	4.2	7.6	3.2
SOUTH						
South Atlantic:						
Delaware	9.3	3.1	11.7	4.5	7.9	3.8
Maryland	9.9	3.6	10.9	4.4	8.0	3.9
District of Columbia	12.2	4.9	15.5	7.5	9.9	5.3
Virginia	10.2	4.1	12.9	5.8	8.4	4.4
West Virginia	14.6	8.0	21.3	11.7	12.3	7.9
North Carolina	12.4	5.2	15.6	6.8	9.7	5.3
South Carolina	12.5	5.8	15.7	8.2	9.8	5.6
Georgia	13.4	5.8	19.0	9.5	10.4	5.8
Florida	12.7	5.1	14.8	6.6	9.9	5.4

Percent of Persons With a Work Disability as Measured in the 1970 Census, 1976 SIE, and 1980 Census (continued)

Divisions, regions, and states	1970 Census: Percent of persons aged 16 to 64 with		1976 SIE: Percent of persons aged 16 to 64 with		1980 Census: Percent of persons aged 16 to 64 with	
	a partial or complete work disability	a complete work disability	a work disability	a complete work disability	a partial or complete work disability	a complete work disability
East South Central:						
Kentucky	13.4	6.4	18.7	8.4	11.4	6.8
Tennessee	12.8	5.7	17.3	8.4	10.4	6.1
Alabama	13.7	6.3	16.8	7.9	10.6	6.2
Mississippi	15.2	7.6	18.8	9.5	11.8	7.1
West South Central:						
Arkansas	16.0	7.4	19.6	8.2	12.7	7.3
Louisiana	12.7	6.2	17.1	7.8	9.6	5.4
Oklahoma	14.4	6.0	16.5	6.2	10.8	5.4
Texas	11.1	4.0	12.8	4.9	7.6	3.7
WEST						
Mountain:						
Montana	11.7	4.0	14.0	5.0	8.1	3.2
Idaho	13.2	4.2	13.5	4.5	8.7	3.5
Wyoming	10.6	3.3	11.3	3.7	6.1	2.2
Colorado	10.8	3.2	10.8	3.9	7.2	2.9
New Mexico	12.1	4.7	13.1	6.3	8.2	4.2
Arizona	13.0	5.0	14.3	5.7	9.1	4.5
Utah	11.0	3.4	12.1	3.7	7.5	2.7
Nevada	9.5	2.8	11.8	3.9	7.8	3.1
Pacific:						
Washington	11.6	3.7	12.5	4.7	8.8	3.7
Oregon	13.2	4.3	13.8	4.3	9.9	4.0
California	11.8	4.4	12.5	5.8	8.2	4.1
Alaska	7.6	1.7	7.5	2.1	5.4	1.8
Hawaii	7.4	2.6	9.2	3.5	5.9	2.6

Among those with no physical activity limitations, over 90 percent of the population, there was little disagreement between the two surveys and the net difference is prevalence rates between the two sets of data was less than one percent.

Among those with physical activity limitations, however, the differences in response consistency are large and appear to account for the major portion of the differences in prevalence rates between the two surveys.

It is a plausible inference that the activity limitations questions preceeding the work limitations questions in the CRS give the respondent a different perspective and a more realistic context in which to consider the work limitation questions.

Plausible inferences can be misleading and the evidence so far is too thin to place any great reliance on. It does tie in well with the results from the SSA and NCHS studies shown in Table 1, since both studies provide more context for examing health conditions and associated limitations than the census surveys. It also suggest some of the directions we should go in developing better information and measurements on the disabled population.

Conclusions

It is apparent that the past decade has not been notable for innovations or new starts. The decade has been characterized more by the consolidation of existing programs. While less exciting than innovation, this is a necessary step in growth and in the assessment of what works and what doesn't. In the case of programs such as Education for Handicapped Children this consolidation has also been marked by a sizeable expansion and institutionalization into the educational system.

In terms of disability data, the accumulation of surveys has provided us with an opportunity to review our methodology and to improve the methods for identifying the disabled. It is apparent that a great deal of work is needed in this area.

The major change in disability conceptualization which should be noted is the growth of the disability activist movement. The emergence of the concept is marked by its very absence from the discussions which took place at the first Switzer Memorial Seminar. Its growing sophistication is aptly illustrated by the papers of Harlan Hahn and Bill Roth at this conference. I question the extent to which the minority group definition espoused by these participants will be useful or productive, other than for political rhetoric. Its uses, however, still remain to be explored in future research. □

Table 5A

Extent of Work Disability: 1980 Census and Content Reinterview Survey, Age 16-69

	MEN		WOMEN		TOTAL	
	1980 Census	CRS	1980 Census	CRS	1980 Census	CRS
Work Disabled	10.5	13.1	8.9	12.3	9.6	12.7
Not Work Disabled	89.5	86.9	91.1	87.7	90.4	87.3
	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
1980 Census & CRS in Agreement		91.0		90.8		90.9
Work Disabled in both		7.3		6.0		6.6
Work Disabled in neither		83.7		84.8		84.3
1980 Census & CRS not in Agreement						
Work Disability in Census, not CRS		3.2		2.8		3.0
Work Disabled in CRS, not Census		5.8		6.3		6.0
		100.0%		100.0%		100.0%
TOTAL						
--Net difference		'2.6		'3.5		'3.0
--Gross difference		9.0		8.1		9.0
Sample Number:		(7730)		(8591)		(16420)

Table 5B

CRS

	1980 Census (April)		
(Nov 80-Jan 81)	Work Disabled	Not Work Disabled	Total
WD	69.0	6.7	12.7
Not WD	31.0	93.3	87.3
	100.0%	100.0%	100.0%
Sample Number:	(1582)	(14838)	(16420)
Percent	9.6%	90.4%	100.0%

Table 6

Work Disability Status by Age: 1980 Census and the Content Reinterview Survey, Age 16-64

	16-54		55-64		16-64	
	1980 Census	CRS	1980 Census	CRS	1980 Census	CRS
	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
Work Disabled	5.7	8.2	20.5	25.0	8.3	11.1
Prevented (Unable)	2.4	3.6	13.3	17.1	4.3	6.0
Partial	3.3	4.5	7.2	7.9	4.0	5.1
Not Work Disabled	94.3	91.8	79.5	75.0	91.7	88.9
Sample Number		(12601)		(2701)		(15302)
		76.7%		16.4%		93.2%

Response Consistency			
1980 Census & CRS Agreement	**92.5**	**82.3**	**90.7**
Both Work Disabled	**2.8**	**12.5**	**4.5**
Neither Work Disabled	**89.7**	**69.8**	**86.2**
Census and CRS			
Partial Agreement*	**0.8**	**2.8**	**1.1**
Census And CRS Not in Agreement			
Work Disabled in Census, not in CRS	**2.1**	**5.2**	**2.7**
Work Disabled in CRS, not in Census	**4.5**	**9.7**	**5.5**
CRS - Partial	**3.1**	**4.6**	**3.4**
RCS - Unable	**1.4**	**5.1**	**2.1**
Net Difference	**2.4**	**4.5**	**2.8**
Gross Difference	**6.6**	**14.9**	**8.2**

**Both report person as disabled, but not to same extent.*

Table 7

Work Disability by Physical Movement Status: 1980 Census and the Content Reinterview Survey, Age 16-64

	Physical Movement Limitations			
	Limitation Since Before 1980		**No Difficulty**	
	1980 Census	**CRS**	**1980 Census**	**CRS**
100.0%	**100.0%**	**100.0%**	**100.0**	
Work Disabled	**52.6**	**74.9**	**5.4**	**6.2**
Prevented (Unable)	**35.7**	**51.9**	**2.5**	**2.5**
Partial	**16.9**	**23.0**	**2.9**	**3.7**
Not Work Disabled	**47.5**	**24.9**	**94.7**	**93.8**
Sample Number		**(1447)**	**(14627)**	**(16420)**
		8.8%	**89.1%**	**100.0%**
Responsive Consistency				
1980 Census & CRS Agreement		**59.7**	**92.8**	
Both Work Disabled		**38.8**	**1.9**	
Neither Work Disabled		**20.9**	**90.9**	
Partial Agreement*		**9.6**	**0.6**	
Census and CRS Not in Agreement				
Work Disabled in Census not CRS		**4.0**	**2.9**	
Work Disabled in CRS, not Census		**26.4**	**3.7**	
CRS - Partial		**12.7**	**2.6**	
CRS - Unable		**13.7**	**1.1**	
Net Difference		+22.4	+0.8	
Gross Difference		30.4	6.6	

**Both report person as disabled, but not to the same extent.*

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Excerpts of Reviews and Comments

The following are excerpts of reviews, comments, questions and recommendations made by the Switzer Scholars. These are presented to further stimulate thinking, discussion and action as relates to the contents of Chapter Two by Lawrence D. Haber.

The subjectivity itself of many survey designs provides for a plethora of speculative comments. However, if one embraces a utilitarian concept in the application of the results and analyses of demographic studies, then I feel compelled to make one observation. Approaching the task of making recommendations for future policy and program development with the assumption that the results of such studies will provide the framework, produces a staggering dilemma. There appears to be in several studies I have attempted to incorporate in policy recommendation, a wide disparity between the responses gleaned from the study and the reality of the vocational rehabilitation state agency experience. One is prompted to first question the instrument and whether its design was such as to elicit the desired feedback. However, I tend to feel that put in its proper perspective, just as any "tool" should be, it can aid in at least surfacing questions concerning the "real situation out there." The missing link appears to lie between the demographic study and the decision to incorporate **new** or **revised policy.** More often than not, the study is discarded as being worthless and having no application to the concerns at hand; or it is accepted on its own merit with no further examination of its relationship to the perceived experience of the program in question.

-- JANICE A. WOODWARD

This paper includes among its highlights several issues concerning "disabled -- rehabilitation" language. They include the language itself as emphasized other places in the seminar; definition and proper usage of terms; the need for frequent and substantive communication between involved parties; and the need for the continual development and updating of the information communicated by the language.

Certainly, the foundation upon which an understanding of the entire field by its various players as well as the general public depends on a full, valid and current base of knowledge developed from clearly stated and commonly applied definitions and methods. From such understanding should flow rational approaches in terms of **intervention** and **reform methodolgies.**

The author points out key problems in the structure and dynamics of our language and its usage. The general and disabled population, policy makers, program developers and practitioners from all service disciplines require such communication systems to exchange valid information in a timely manner for timely action.

Attention to this area should be of high priority particularly as regards more accurate estimates of disability prevalence and its subcategories.

The data which the author demonstrates to have been of greater consistency across several measures including time, require immediate program planning attention. In addition, consistently defined socioeconomic and geographic pockets of disability require attention with the purpose of raising individual functional levels while contributing to the viability and further maturation of our economy and society.

In this regard, most assuredly there is some greater impact that the field should be making on the plight of the 35 to 40 million poor in our midst and in the midst of such affluence.

Again, we should look to those consistent socioeconomic correlates for such attention of high priority. The staggering figure of 40% unemployment among black males in the working age population is devastating. When we remember that almost one-fifth of the total black population in that age group have some disabling condition, the potential impact on effort for the rehabilitation field focuses most clearly. Such efforts should be both direct and indirect, but certainly of an innovative and humane manner. In addition to the traditional services, professional advocacy and the support of the self-advocacy movement, should be encouraged to catalyze the long road beginning with desegregation leading to integration of disabled persons into our society. Similar challenges exist for us among the poorly educated and older persons.

Finally, the field should exert its influence more in the **prevention of disability.** Professionals can participate in lay groups, as well as professional organizations which have this goal as part of its agenda. Further disability prevention should become a more conscious determinant and ingre-

dient of the day-to-day operations of planning in the rehabilitation setting.

-- HERBERT THORNHILL

This paper is generally well written and thought provoking. It ends somewhat abruptly, and it would have been interesting to have the author identify conclusions and suggestions for the future based on the information he presented.

The issue of standardization of definitions is extremely important, and also extremely difficult to achieve. Certainly the acceptance of **standard definitions** will impact the collection of data. This, in turn, will impact policy and planning for services, funding, priority funding, staff training, and so forth. Unfortunately, the author does not attempt to present standardized definitions, but only raises the issue of need. In addition, the definitions commonly used in the State/Federal Rehabilitation system are not included.

The relationship of questions asked in surveys and the order of those questions could be further explored. Perhaps **model questions could be developed** and adopted by all government and private agencies, with subquestions added for specific purposes, in order to both make data comparable and eliminate duplication of effort. This could save both time and money, as well as result in more valid and reliable data.

An issue Haber fails to address is that of **age definitions** for work status. Is it possible that persons can work after the age of 64? What has been the impact of extending the retirement age to 70, and of prohibiting employment discrimination between the ages of 40 and 70?

We know that the rates for disability increase with age. To collect data on persons 15-54 and 55-64, as its commonly done, results in a loss of much potentially useful data on incidence and prevalence rates by age. Planning for medical care and rehabilitation services for a person in their 20's differs from the same planning done with an individual in their 40's, 50's, or 60's. The lack of specific data for the various age groups also fails to account for the relationship between chronic diseases and disability. When do chronic diseases, such as high blood pressure, progressive nerve deterioration, or peripheral vascular disease become disabling?

In summary, then, Haber points out some important issues to consider in data collection, which has a significant impact on policies and programs for disabled persons. Among the issues he raises that merit discussion should be added the importance of **defining age categories when describing disabled persons** demographically.

-- JANE E. MYERS

Programs appear to go merrily on their way refining the measurement of the traditional distinction between impairment, functional limitation, and disability. What about "handicap" that results from discrimination by non-handicapped persons? Why has the bureaucracy and the academic establishment been so loath to tackle this? Surely there is a message here. Other elusive concepts, such as the "achievement motive," "the social desirability response set," etc. have received their due. Why not handicap?

It is always good to detect relative stability in repeated surveys of any phenomenon, especially when any differences in prevalence can be attributed to differing methodologies. It is a tribute to Mr. Haber's long-standing dedication to measuring disability and its trends in the U.S. population that we have as much understanding as we do for these things. That much money continues to be spent on the measurement of disability is rooted in the economic motive; Federal programs spend billions of dollars on disability and require forecasts of likely changes in prevalence by various definitions.

Would that the U.S. government spent as much **on the evaluation of program effects** on the lives of disabled people -- especially in the sphere of rehabilitation. Without such knowledge, we must continue to aim public objectives, at restatements of good intentions instead of support for grounded knowledge of **what works and what does not work.**

Given the paucity of data about the program effects of myriad public and private programs aimed at "rehabilitating" or otherwise helping disabled people to secure the benefits of citizenship, this conference might well address how prevalence and demographic studies can be joined with program data to show how well we are actually doing in improving the lives of disabled people.

What are the possibilities? Do we have any new ideas? How difficult are they methodologically? How costly? What, if anything are the Swedes doing that looks interesting. The archival data systems of Sweden have long intrigued me because of their potential for linking life-long records of individual and group transactions with public and private organizations.

Finally, we must finds ways to gain reapproachment with the World Health Organization (WHO) about the impact of differing socioeconomic and political systems on the prevalence of all facets of disability (impairment, functional limitations,

disability, and handicap). In my view, other countries are more likely to employ the WHO scheme than the U.S. conventions because of international politics. Are there any steps being taken to devise studies which attempt empirical measurement of the WHO definitions? Without such studies the United States is doomed to splendid isolation.
-- JOHN H. NOBLE, JR.

In presenting this comprehensive summary of demographic data, Larry Haber has made a valuable contribution to survey research on disability which represents a continuation of the extraordinary record of research that he has compiled previously. My quarrel, therefore, cannot be construed as disagreement with his work or his analysis. Instead, I feel compelled to offer some comments about more basic issues of conceptualization.

The problem, as is so often the case, seems to rest on definitions. As shown in the chapter, the understanding of disability employed in this paper is really a definition of the somewhat more limited phenomenon of "work disability." Despite the assumptions embedded in public policy, the two terms are not necessarily interchangeable. Perhaps a brief anecdote might illustrate the point. Several years ago a colleague, aware of the fact that I had used crutches or a wheelchair since I had polio at the age of six, called to pre-test a questionnaire on me. One of the questions asked, "Are you limited in the amount or kind of work that you can do?" Since I am perfectly happy with my job and have seldom thought of doing any other type of work, I instinctively replied "no." "But," he interjected, "you can't answer the question that way. After all, you couldn't be a quarterback for the Los Angeles Rams." My response again came really without conscious thought. "But neither could you."

The incident, I think, not only demonstrates that disabilities are relative; but, perhaps even more significantly, it also indicates the type of subjective judgement which is required by a question of this nature. I interpret Haber's finding that "the activity limitations questions preceding the work limitations questions ... give the respondent a different perspective ... in which to consider the work limitations questions" in this context. Questions about "work disability" compel the respondent to make a mental calculation about the fit between his or her impairment and available employment opportunities. While some respondents may make a conservative assessment of this relationship, others might construe it more liberally. The consequence may be the type of variability in estimates of prevalence which Haber rightly identifies as a major problem in survey research about disability.

Moreover, existing questions about "work disability" provide few clues about the sources of the alleged relationship between disability and unemployability. They merely assume such a relationship without considering the possibility that the fault may lie in the economic, political, institutional, or architectural environment rather than in the individual. In his discussion of Section 504, Haber is correct in noting the lack of "studies which have attempted to use the statutory definition as a basis for identfying or defining disabled persons." But this does not mean that the potential contribution of a minority-group definition to survey research on disability must be dismissed. As I have indicated elsewhere, such questions could be divised utilizing the concepts of visibility and permanence as well as the notion of a disability continuum. These methods seem to deserve attention commensurate with the prior emphasis which has been placed on the operational definition of "work disability." The results of such investigations could contribute significantly to unraveling the problem that have plagued previous survey research on this subject.
-- HARLAN HAHN

Haber presents some interesting data representing demographics on programs for disabled persons across the country. When reviewing such data we must keep in mind the "functional limitations" associated with "demographic survey research." Although we have sound statistical principles that govern our use of such data, we must realize statistics have no "emotions, values, attitudes, or beliefs." Interpretation of such data, with the intent to transfer this information into appropriate programs must be guided by the "external and internal" issues that are not easily factored into empirical research.

Data of this nature cannot stand alone, nor should it be the mortar in the foundation of the building. In other words, as professionals we often rely on statistics and equate them to the substance and the foundation of the programs created to serve disabled persons much too readily.

If we keep these data in proper perspective, we can use them as peripheral information and rely more on our attitudes, values, and beliefs to impact on the trends of rehabilitation as they relate to modern technological programs, keeping in step with societal changes.
-- WILLIAM A. CALZARETTA

Switzer Scholar Roth

Chapter Three

The Politics of Disability: Future Trends as Shaped by Current Realities

By William Roth

Attempting to predict the future from the present is a delicate undertaking. Prudence has it that the future will look pretty much like the present. Being prudent, then, one might describe future trends as continuing present trends. And one should certainly not make predictions that change the rules.

While prudent, such fortune telling is not particularly interesting. Therefore, as the politics of disability has changed itself and the rules radically and irrevocably during the last decade, to be prudent here would be inaccurate. Not only has disability changed, marked by a self-conscious thrusting of disability into the political arena, questions regarding this society on how disability is viewed and defined have changed as well.

In the following passages, I shall examine current realities and future trends of importance. These include what has been gained and lost by using a minority definition of disability, why giving up such a definition may become an irresistable temptation in the near future and why that temptation should be resisted. I also caution against the fashionable assumption that all oppressed people are natural allies. I shall inspect the escape by disability from the clinic into bureaucracy, questioning what effects that transition may have. Further, I will discuss the ethics that spring from bureaucracy, questioning its wisdom and appropriateness and finally, I will address some of the possibilities in high technology with regard to bureaucracy and the shrinking real domestic public resources.

Intellectually and politically, disabled people are a minority and face a host of problems faced by other so-called minorities. As a minority, persons with disabilities also face problems and opportunities befitting their particular status. I do not propose to argue the case for a minority definition of persons with disabilities here; that debate apparently is largely over. On the other hand, some other definitions of disability will illustrate what has been lost as well as gained by disability in the transition from these definitions into both the self-definition and definition by others viewing disability as a minority group.

At first blush, it would appear that not all that much has been gained over the years. Neither the Republican nor Democratic candidate for President or Vice-President spoke about persons with disabilities in their acceptance speeches in San Francisco and Dallas, respectively. The incumbent Vice-President had ample chance to take up the issue of disabled people as a minority, having been charged with the task force on deregulation which, *inter alia,* considered the regulations pursuant to Section 504 of the Rehabilitation Act of 1973.

At the beginning of the last administration one Congressman felt obliged to point out that Ed Roberts' presence on the Hill was touching. Roberts*, restricted to a wheelchair, had courage enough to relentlessly pursue his Congressional goals; something not seen by many members of Congress.

More recently, the last muscular dystrophy telethon raised unprecedented amounts of money. Aside from other negatives associated with that type

* Former State Director of Vocational Rehabilitation in California

of media venture, the monies benefitted those with muscular dystrophy and decreased the chances of others acquiring it. Although the telethons have been drycleaned of some of their obnoxious characteristics, we are still led to admire the courage of the "poor little cripples" in their individual struggles which fate incarnated as handicap. That this appeal works so well at the same time that many minority programs for disabled persons are in trouble is testimony to the charity of our people. If ever there was a worthy group of poor persons it must be persons with disabilities.

The affair of Baby Jane Doe is a most complex one. Although federal intervention was predicated on Section 504, a civil rights section of the Rehabilitation Act of 1973, and although support by many disability groups was predicated on civil rights considerations, it is questionable whether government action and popular response were predicated on disability politics or right to life politics. Perhaps here, as so frequently the case in politics, the bedfellows were strange. Perhaps one should not make too much of the strangeness. On the other hand, the concern of the right to life movement for disability seems limited to rights *in utero* exclusive of rights *in terra*. The situation was complex, the allies strange, the issue confounded by press, public and politicians, and the victory somewhat ambiguous.

If the minority definition of disability has fallen on hard times, so too, not coincidentally, have the minorities themselves. The feminization of poverty, nutrition of America's poor children, unemployment amongst blacks, and a plethora of other issues concerning minorities have emerged with new force. But it should be no surprise that in a time of shrinking domestic public resources marked by a diversion of resources away from minorities, events should not be passing well. Perhaps the minority definition of disability has done persons with disabilities wrong.

Recollect the historical circumstances surrounding the adaptation of the minority definition of disability. The moral drama of the Civil Rights Movement was ongoing history. The anti-war movement was partially succeeding. The Women's Movement was propelled from changing economic circumstances to success after success. Public policy has recognized the need for dramatic change. In short, the minority definition of disability was accepted not only on its intellectual merits, but on the promise of the achievements of other minority movements. Today's politics jeopardize all. It may well be true that adhering to the minority definition of disability must, in the end, be based on the intellectual and moral rightness rather than on mere drama and promises.

Have there been gains resulting from the minority conception of disability? Or has the minority definition of disability led to consistent disaster? Quite the contrary, as it has led to spectacular advances in the past decade. If these advances have not increased swiftly it is due to the nature of politics, an arena into which the minority definition of disability has fallen.

Early court cases eventually led to the passage and implementation of the crucial Education for All Handicapped Children's Act of 1975. An even more dubious success was the White House Conference for Handicapped People, which raised the awareness of many who attended, and an awareness to be shared later with others at home. The most remarkable successes, though, concern Section 504 of the Rehabilitation Act of 1973, the issuance of its regulations and compliance to them by recipients of federal grants, all of which articulated to the minority definition of disability. From these instances and others like them it became easier to look one's disability squarely in the face. A new measure of self-respect issued forth from the social definition of disability as a political minority.

The film "Coming Home", if not inconceivable, was rare and a short while earlier "The Men" had been a sensitive, powerful, and singular film following the Korean War. If "Whose Life Is It Anyway" was a poor film, telegraphing the events that may well lead to another film ("The Bouvia Affair") it at least did not take for granted that disability was lamentable, regretable, or horrible. And "The Elephant Man" and "Children of a Lesser God" were not disasturous. Most remarkable is not so much the individual films, but the corpus of films and television shows, plays, and other media events dealing with disability and its problems, both personal and societal.

Dramatic political acitons predicted on the minority definition of disability took place with regard to federal attempts to weaken the Education for All Handicapped Children's Act, wherein alliances were made and categorical grants for target populations maintained. The level of political skill and involvement did not reach its ultimate, however, until threats to Section 504 (of the Rehabilitation Act of 1973) were perceived and codified in a meeting of the disability Rights and Defense Fund on September 20, 1981. This event led to the presence in Washington of a spokeswoman for disabled activitists, a grass roots movement and the demonstration of political sophistication not yet seen in the disability rights

movement. One effect of the minority definition of disability was to educate disabled people in the use of the political process.

As if to assure the disability community of its minority status, the administration grouped 504 together with Title VI and Title IX, which protect traditional civil rights constituencies and the newer constituency of women. The failure of attempts to weaken the regulations is properly seen as an enormous victory for the disability rights movement. That it is not perceived as such by many is indeed lamentable and tends to overlook disabled people as a political force.

The preservation of the act is, of course, conservative as it does not clear new ground. But a conservative victory is nonetheless a victory for the conservation of human rights in a time of radical administrative policies.

There were numerous legal battles with some wins and some losses. But the raising of questions regarding disability into the courts marked a victory of sorts regardless of their outcome, and placed the disability rights movement right on center stage.

In sum, persons with disabilities live in a better world than they did before the adoption of a minority definition of disability. If that world is not perfect, neither is life. Of course, this summation is much too simple. The world is not perfect for numerous reasons involving *inter alia,* oppression, discrimination, and a general lack of resources.

The minority definition of disability has been a mixed blessing. That is to say, if scarcer domestic federal and private resources have been diverted to disability programs from other minority groups, it is a sad moment on the aptness or utilitarian usefulness of the definition. Unfortunately, times continue to be rough for minorities and may be even rougher in the future. Who in such a situation would like to be classified a minority?

Disability can be chameleon like if it so chooses. In the near future it is likely to avail itself of various definitions. It may well be that in the next four years many gains will be threatened. I would suggest, though, that a retreat from a minority status in favor of a clinical status, a deserving poor status, a weak status, etc., would be a fundamental mistake. Disabled people will lose to the extent that other notions of disability once again permeate discourse and life.

There are intellectual niceties, practical concerns and political problems with the minority definition of disability. For example, disabled people are an unusual minority in that most often neither their parents nor their children have been or will be disabled. From a practical viewpoint there is difficulty in getting concensus on this issue. This is a result not only of the poverty status of disabled people, but of a lack of access to buildings and transportation as well. Politically, a significant problem has to do with disabled people speaking with one voice, if this is indeed possible. Perhaps this problem has virtues connected with it, a diversity of view, a plurality of interests, and an intellectual ferment. In many ways, it is similar to the situation of Blacks, Hispanics, Native Americans, and women. For example, the interests of all women are not identical. Certain issues ferment the women's community, with child rearing and abortion being just two significant areas of differences.

The disability movement would seem to have another sort of problem since there are many different disabilities. Each disability, or so it has traditionally been argued, has a special set of needs. It is difficult, therefore, for disabled people to unite on any one issue. Diversity, however, in the disability community is like diversity in other minority communities. It usually is the social and political construction of disability by others which defines our needs, perspectives, and interests as different.

In what sense can the young, often middle class, mainly white persons associated with the Independent Living Movement or, at least, their leadership, claim to speak for the institutionalized retarded person, the older disabled persons, the disabled veteran, the person disabled on the job, the multiple disabled child, the person on Workman's Compensation, and the recipient of Social Security Disability Insurance? How can diverse groups be folded into any one definition, march under any one banner, or organize together politically? The question is a difficult one to answer.

A coalition of disabled persons can be forged by techniques common to other political groups. For example, the Democratic party could hardly be said to express one interest. As has long been noted, the Democratic party is less homegenous than the Republican party. Nonetheless, at least until recently, the Democratic party was able to forge coalitions sufficiently powerful to capture the Presidency and, even more so, the Congress. This sort of politics is well documented by American political scientists. In some measure, it is the sort of politics practiced by disability groups both with a their internal constituencies and in their increasing alliances with other minority groups. And yet it should not be expected that just because such traditional coalitions are not necessarily weak that such traditional political coalition-building leads to the strongest of coalitions, much less to the forging of a single identity.

There is another way that disabled people might conceive of themselves as one minority groups -- the Independent Living person having something profound in common with the other people mentioned. This is the sense in which disability is a construction of the other. To the degree that construction by the other stigmatizes all disabled people, disabled people have a certain stigma in common. Further, they should have a common mission to deal with the oppression that usually comes with that sentiment.

This definition of disability by negation, oppression and by the other has the advantage in that it leads to political action. Its disadvantage is that, in the end, a definition by negation promises no more by way of dignity than does a defintion by way of illness.

There are, however, intellectual reasons leading to the minority definition of disability that make for a shared perspective among people with disabilities. To explore this, I briefly mention what seems to be a reasonable characterization of disability.

A disability characterizes the experience of anyone who experiences the world mediated through a different body than others. Insofar as the world is made up of many "others," this includes the definition by negation. But also extends beyond that, starting with the anatomy and physiology of the body including a body that is human, incarnate and possessing an intentionality that makes, for instance, a retarded person's body different from that of a person without retardation (bracketing the considerable difficulties involved in deciding what retardation is). Although the anatomy of a person with severe cerebral palsy is likely to be similar to that of one without, the body imbued with intentionality will be different. It is the experience of disability that is a sound intellectual, theoretical, and political basis for the unification of disability under the minority definition. This experience of disability is shared by the person in the Independent Living Center, the multiply handicapped child and a wide range of others. They all have bodies and all are human. They all have bodies different from the bodies of persons without disabilities. That certain people with disabilities are at the forefront of consciousness and political action hardly makes disability different from other minority groups. Thus, in the same sense that leaders in the women's movement can claim to speak for all women, leaders of the disability movement can claim to speak and often do, for all persons with a disability.

There is a caveat here. In **Rehabilitating America**, Frank Bowe proposes a natural alliance between old people and disabled people. In fact, such an alliance is *not* natural. The disability movement and various movements of old people have had little in common.

The experience of enfeeblement is different from the experience of handicap. Enfeeblement is the loss of powers once had. It usually is progressive. Its terminus is death. It may well be genetically programmed, as may indeed be psychological concomitants to it. It comes at a certain time in the life cyle, usually beginning about 40, when one has attained a plateau in one's career. The midlife crisis, a common subject for pop-psychology, is in large measure a crisis of the birth of enfeeblement.

Unlike disability, enfeeblement is usually unwelcome on its purely biological face, taking no social construction to make it disturbing. Further, the social construction of enfeeblement does not ususally allow for the measures available to the disabled. What, for example, is the sense of training an 80-year-old whose sight is failing to use computer devices that make sense for visually impaired vouth?

If the social construction of old age is disgraceful to this country, the roots of disgrace are different from the roots of disgrace of the social construction of disability, partially because the enfeebled were once our parents with power over us. Enfeeblement carries a different social construction and biological substate, and phenomonologically speaking is experienced differently from disability.

Old people are not the natural allies of disabled people. That the social construction of old age and disability grow from different roots and have different effects, although the same in their disgracefulness, signifies that appropriate policies for the disabled persons and elderly persons are apt to be different. For example, while many disabled people look upon transfer programs as devices to buy them off from the job market, many elderly people welcome these payments regarding them as money due for a lifetime of work.

Although old persons and disabled people are not one, they can be and have been allies. But disability organizations should never be predicated on the illusion that oneness is to be sought after. The distinction between disability and enfeeblement helps us understand otherwise puzzling aspects of programs like social Security, Social Security Disability Insurance, Medicare, Medicaid, etc.

Among other things, I have discussed how disabled people have fared under a minority definition of their situation, about the political impacts this creates and about its implications for the future. There is a different order of questioning that must

be addressed as well. This has to do with the nature of the society where we all live.

The observation is commonplace. Today, overwhelming portions of our lives take place in bureaucracies. Most of us work for bureaucracies. All of us are served by bureaucracies; some more than others. And, sometimes we may feel victimized by them.

Bureaucracies are increasingly the arena where the disabled persons are thrust. Increasingly, the decisions affecting the lives and deaths of disabled people are made in bureaucracies, by bureaucracies and, arguably, for bureaucracies. Law concerning disabled people is increasingly administrative. There is a threat here in that the thrust of bureaucratic control is to obscure the political nature of social action. We have all entered a bureaucratic [illegible] persons with disabilities included.

The interactions of the disabled person with bureaucracy have received scant attention. Occasionally there are articles about the vocational rehabilitation client or special education student and the profession. But the contact of bureaucracy with those whom it serves or victimizes has not been a subject of major concern. Most recently, in a provacative monograph for the World Rehabilitation Fund, Joseph Stubbins urges that individual problems be considered in relation to a broader social system including one would presume, the bureaucracy.

Bureaucracy must not be thought of as solely in the public sector, bureaucracy in America orginally being a child of nineteenth century industrialization. A bureaucracy is a hierarchical organization with position, and job description, dominating the organization.

The most illuminating and profound scriptures on bureaucracy remain those of Max Weber, who likened bureaucracies and people to factories and things. From France, Thomas Jefferson brought the idea of interchangeable parts, an idea established by the inventor Eli Whitney, and embellished by Henry Ford. Interchangeable people are vital to the complex organization of modern bureaucracy.

But for a bureaucrat to be interchangeable with another bureaucrat presumes interchangeable lived bodies. Bureaucrats may not like their job or may be unsuited to them, etc. The after-work martini therapy, or running around with the girls and boys may shave the squareness off the peg. For disabled people the problem may be more profound. It may be that the disabled person simply cannot, and I use the negation advisedly, perform a job designed for the able-bodied. In order that the job be interchangeable, the body that performs it must be interchangeable as well. But disabled lived bodies tend to be different from each other as well as different from able bodies. In this sense disabled people may be inherently anti-bureaucratic.

Legislation, like 504 and 94-142, is modified by bureaucracies so as to alter the lived body of the disabled person, and to find bureaucratic niches by teaching new skills and devices of adjustment to permit the disabled person to function in able-bodied bureaucracies. While seemingly anti-bureaucratic in that they explictly deal with individual cases -- what could be more individual than an Individualized Educational Plan -- these laws increasingly make the anti-bureaucratic disabled lived body as interchangeable as possible with the able body. In other words, their effect is to lead from uniqueness to the standardization of mass production and bureaucracy.

Arguably, this has always been the thrust of American Civil Rights movements which seek a way in. Perhaps the minority definition of disability recognizes that disability is socially and politically constructed and that it is equally society's obligation to bend, adjust, and to cope as it is the disabled persons? Modern day exercise of 504 and 94-142 increasingly subvert the original intent as does most of the apparatus of vocational rehabilitation, special education, rehabilitation medicine, etc. Although these were built without the illumination of the civil rights of disability.

Of course, significant aspects of bureaucratic organizations break no harder nor easier on disabled people than on able bodied people. Thus, hierarchical organization is not harder for a disabled person except to the degree that those higher in the hieracrchy may be misunderstanding of disability. Frequently disabled people progress through bureaucratic organizations through the good will of a boss.

Meanwhile, the steps to advancement may be differently navigated by a disabled person. Consider the canard where the boy starts as a stock clerk, marries the boss' daughter, and by hard work in every odd job winds up toward the head of the bureaucracy. Marrying the boss's daughter is likely to be difficult for a disabled person. Similarly, it is difficult being a stock clerk or secretary for a bright disabled person who may not find it difficult at all to be an executive. Modern bureaucracies have circumvented the job ladder problems to some extent by requiring training in schools and other organizations that can modify themselves more after the needs of the disabled person. Nonetheless, there still is a problem of differential access to dif-

ferent roads to the top. The statistics of hieracrchy sometimes might seem to argue for the disabled person, but the dynamics of hierarchy seem to argue against the disabled person's progress.

Through a different body, it may be that the disabled person expresses more poignantly the bending and sometimes breaking of the able bodied person into bureaucratic function. The disabled person simply will not bend as easily. It is a lesson worth the attention of both able and disabled bodies.

Disabled persons are also clients of bureaucracy. As outsiders, we have all experienced the arrogance of bureaucracy. Doubtless some of our more precious personal anecdotes deal with applying for an automobile license, a marriage licence, a school course, or a myriad of possiblities that penetrate the space of our lives. On occasion, in these encounters, we have felt abused by bureaucracy. Doubtless that person has said, "I'm sorry, this is company policy," or "That's the way things work," or "Why don't you come back next week."

This discrepancy in power is at least as true with disabled people in their dealings with bureaucracy. And, indeed, a part of the social construction of the experience of disability is exposure to many bureaucracies. Whether the bureaucracy is medical, social service, vocational rehabilitation, special education, or any of the others, the disabled person will probably contact them hard and frequently. By doing so the disabled person is likely to experience the rebuff that the able-bodied person turns into a joke too frequently to joke about. As irritation becomes pain and as pain becomes internalized, the disabled person may learn how to be the recipient of bureaucratic largess.

This is not to say that the fault lies with the bureaucrat. The vocational rehabilitation caseworker, for example, may have job performance measured partially by the number of cases closed. It is a disincentive to try for more difficult placements; an incentive for mediocrity. Such perverse incentives exist throughout the bureaucratic system. In so far as bureaucracy might be thought of as serving clients, these incentives should be changed.

But what if the goal of bureaucracy is not to serve a client, but rather to serve itself, policy makers, other organizations, or higher points in the hierarchical pyramid? What might appear to the client and, indeed, to the line workers as a perverse incentive in fact may be beneficial at some other organization level. For example, the frequent bureaucratic disincentives in receiving transfer payments may appear perverse from the point of view of the recipient. Nonetheless they cut down the number of claims and the number of claims honored thereby limiting budgetary outlays necessary, therefore proving rational to others.

Bureaucracy is a phenomena with consequence for theories of ethics. One ethical philosophy that goes with it is utilitarianism, a contribution of Jeremy Bentham, refined by John Stuart Mill, embodied in bureaucracies. Utilitarianism, defined as hierarchical domination of production completes the bureaucratic ethic and propels it forward into a world that bureaucracy does not yet dominate.

Utilitarianism measures an act by its success in attaining the greatest happiness for the greatest number of people. This version of utilitarianism has been analyzed by modern economists and found without operational merit. They have substituted for it the notion of Pareto optimality, which says it is bad to hurt anyone unnecessarily and good to improve the utility of any person as long as it does not detract from the utility of anyone else. This option of Pareto optimality has made one further transmutation in modern utilitarianism, namely that something is good if the gainers to a transaction could compensate the losers. On this proposition modern welfare economics is constructed, a derivative of which is the form of analysis used to gauge the value of programs and which starts to permeate the law. I speak of benefit-cost analysis, in reality an applied form of welfare economics and, as such, an operationalized form of utilitarianism.

There are many problems with cost-benefit analysis. One is its treatment of "immeasurables", hard to quantify entities which nonetheless seem important. But the difficulties are thornier. As Kenneth Arrow has shown, welfare economics, and hence cost-benefit analysis, applies only where decision-making is dictatorial, i.e., non-democratic. In hierarchical bureaucracy, decision making is non-democratic.

Consequences noxious to those concerned with disability flow easily from cost-benefit analysis. For example, according to cost-benefit analysis it would be difficult to demonstrate that large expenditures of money for mentally retarded children are worthwhile. But the disability movement has profound interest in such matters. The disability minority rights movement must question the utilitarian bases of much decision-making from a more sophisticated view of ethics than cost-benefits analysis, welfare economics, and utilitarianism; that is, from a more sophisticated ethics than the ethics of bureaucracy. Whether or not the disability movement is able to make these sophisticated ethical claims and to do

so in a persuasive and political manner will directly affect the future of that movement.

To repeat, are people with different lived bodies disabled people, fundamentally anti-bureaucratic? At certain junctures in a bureaucratic organization the disabled lived body may well fit. For example, a person in a wheelchair might be suitable as a secretary or a top-level manager. The fitting of various disabilities with various job opportunities is a traditional one of vocational rehabilitation. Unfortunately, the incentives of vocational rehabilitation are such that at times the disabled client is placed in a position below his or her capacity. The job ladder leading from that position to another may well not accommodate the disability. With the able bodied persons, the body bends to meet the challenge. For the disabled person, the body may bend and bureaucratic pathways may have to be stretched, but such may be against the structures and proclivities of bureaucracies. People with disabled lived bodies may thus be fundamentally anti-bureaucratic. This, perhaps, expresses the nature of human lived bodies in general. Many of the strategies that the able bodied person uses for coping with a bureaucracy, such as subversion, bending the rules, stretching, bobbing and weaving, may be less available to the disabled person. Changes are required in bureaucracy to make it human. Whether these changes occur has direct bearing on disabled people.

We may be entering a time when bureaucratic changes are possible. Revolutions may be brought to bureaucracies by telpehones, computers, information handling techniques, etc. This technology can insure the domination of those lower in the hierarchy by those higher up. For example, the word processor can measure the time spent working and submit it to a centralized processing unit for analysis. Those at their machines can be called in or fired.

Similar strategies exist with regard to other high technology. Is high technology a means of effortless domination?

There is another possibility not logically contradicting the first which shows the way to liberty for people working in bureaucracies and even more to disabled people working for bureaucracies. High technology promises unparalleled advances in the ability of disabled people to do standard bureaucratic jobs.

For example, blindness used to be a disability that made many bureaucratic jobs difficult. With the advent of talking computers, the visually impaired person can accomplish most jobs involving computers from word processing to programming. As more jobs in modern bureaucracy become attached to computers, it is to be expected that more jobs will become suitable for people who are blind..

High technology, then, is making blindness even more trivial in the work place. This helps provide jobs, dignity, self respect, friendship, and a host of virtues at which vocational rehabilitation aims. These virtues lead to the enhanced independence of the visually impaired person. The use of technology to empower people to have access to education and jobs is powerful and may transform the way in which we think about disability.

Technology as empowerment for disabled people can co-exist with technology as bureaucratic domination. The mix is not the product of any technological inevitability. Instead, it is the product of the organization of our bureaucracies. It is an appropriate focus for the disability rights movement, another reason for the expansion of the disability rights movement into the arena of bureaucracy. Perhaps people are able to be productive without domination, accountable out of responsibility rather than because of surveillance.

Long ago there lived an economist called Malthus, whose name has become synonomous in everyday speech with gloom. Malthus proved that since the human race reproduced itself geometrically while resources increased only arthimatically, the people would eventually outstrip the resources. The industrial revolution proved him at least temporarily wrong, leading to exquisite expansion, technological capability, flourishing wealth, and a period without parallel in the history of the race. From time to time, since that initial industrial revolution, there have been other mini-revolutions that have increased the resources available. We're in the middle of one such mini-revolution now.

At this time when resources going toward the domestic sector are in some cases shrinking and in general not growing as fast as they once did, anything that increases resources will have at least a modest effect on public domestic resources. With the latest mini-revolution it is too soon to tell. Implicit in it is a new and dramatic promise for the disabled. Although its benefits as a whole may be distributed in such a way that disabled people are a little bit better off, the nature of this technology is such as to improve the lives of disabled people disproportionately and dramatically. High technology, robotics, information processing, and computing in general promise to make disability trivial in a significant number of work situations, a development with profound consequences for disability and its social ramifications as well as with vocational rehabilitation.

I have expressed some possibilities and options concerning future trends in disability. As has been obvious, current realities such as the immersion of the disability into bureaucracy, the revolution in national priorities leading, *inter alia*, to the legitimation of greed and the entrance of bigotry into polite conversation, etc., are not entirely happy.

As pessimistic, or perhaps more accurately, fearful, as thinking about the future makes me, I am forced to draw other conclusions as well from that I have said.

The promise of new technology is immense. Like another sort of deinstitutionalization, the dismantling of huge public bureaucracies may have some positive outcomes. The political awareness of the disability movement has increased staggeringly. Wheras 94-142 and 504 were largely gifts, their retention was overwhelmingly the result of struggle and political savvy on the part of disabled people and their friends.

This willingness to struggle and this political savvy are an enduring legacy of the minority definition of disability that will be sorely needed in the future. Their very existence is reason for hope. □

Excerpts of Reviews and Comments

The following are excerpts of reviews, comments, questions and recommendations made by the Switzer Scholars. These are presented to further stimulate thinking, discussion and action as relates to the contents of Chapter Three by William Roth.

I would like to express my concerns regarding Dr. Roth's endorsement of high technology as "empowerment for disabled people."

There is no question that the use of technology for disabled people has powerful potential as an "equalizer" with regard to accessing education and employment, as well as generally opening up areas of physical and communication abilities beyond our current comprehension. On the other hand, is it also not possible that this technology can lead to **further isolation and segregation?** For example, through the use of technology, isn't it possible that a disabled child's classroom can become his or her home?

Similarly, is it not possible that employers will view the work place as home? It can be argued that nondisabled people through the use of technology will also be receiving education and working at home, but can one ignore the element of choice?
-- ANNA FAY

I believe that Bill Roth's paper illustrates clearly the valuable contributions which the minority-group definition of disability can make to the development of policies and problems in rehabilitation. Significant social trends such as the disability rights movement do not operate in a vacuum. They arise from major problems or contradictions in existing policies, and they provide an important intellectual perspective for future planning.

I find little, if anything, in Roth's paper with which I disagree. Our differences are only in emphasis and in tone. At some times, he seems more pessimistic than I am; on other occasions, he is more optimistic. I am not certian, for example, that I share his belief that "the debate (over a minority definition of disabled people) is largely over." The fact that several other papers at this seminar are not founded **on this theoretical orientation** suggests to me that the battle has not yet been won. And yet I find it hard to imagine that anyone who reads his paper would fail to embrace this approach and to discard the traditional premises which guided the study of disability previously. Some, I suppose, may remain unconvinced. But if they are not persuaded, I hope at least that they will make their doubts and objections clear. Too often the discussion of issues in the field of rehabilitation has been clouded by reluctance, especially among nondisabled professionals, to state their true opinions about the minority-group approach. The consequence has been a kind of paternalistic silence which can only yield frustration and misunderstanding. The clarity and incisiveness of Roth's arguments seem to offer an unusual opportunity for meaningful dialogue as well as a rare test of the proposition, which I refuse to abandon, that attitudes can be changed through **rational persuasion.**
-- HARLAN HAHN

Acceptance of the minority status label may itself serve as a **legitimization of discrimination,** i.e., by definition, minority groups are those that suffer from discrimination. This in many cases perpetrates

a stereotype that something is wrong with the person as opposed to a recognition of a societal problem. Certain special employment solutions (Targeted Jobs Tax Credits [TJTC], disabled worker certificates, special incentives) are examples of how special treatment reinforces a condition of differentness and inability. "If handicapped workers are really equal, why do we need special incentives to hire them?"

Minority groups have, over time, been able to assimilate into the dominant culture by demonstrating an ability to take on behaviors, roles, activities, and responsibilities of the majority. The disabled persons it seems, have some very real limits on the extent to which assimilation is possible. This does not refute the value of the minority group analogy, but must be a conscious part of long range strategy to take advantage of its merits.

One of the greatest values of the minority group model is its ability to coalesce large sectors of the population, and (a) establish a political base, (b) develop a sense of pride and self-worth, and (c) bring disability out of the closet and onto the public agenda.

It is not necessaary that all of disabled people speak with the same voice or want the same thing; the key is that **all speak** and **all are heard.** History has shown that many voices -- from militant to moderate -- are necessary to effect change. Could non-violence have been effective without the potential threat of violence? The commonality of interest among the disabled must be the **desire for change** to enable a reality of choice and opportunity. There must also be a recognition that in any minority group movement, there has never been 100 percent participation.

While bureacracy has never existed in the pure sense as envisioned by Max Weber and Frederick Taylor, even the less pure models have given way to more humanistic structural designs. The issue may be the extent to which these more humanistic structures better allow assimilation of disabled persons into organizations. If the utilization of technology becomes a necessity for **all,** then it would appear to advantage disabled people in terms of job performance attributes.

V.R. may be a victim of the cost-benefit paradigm it has created. To the extent it has sold this model, it has limited a serious discussion on alternative values supporting rehabilitation. All good social policy decisions are not economically based, i.e., it is more sound economically to use capital punishment than to incarcerate for life.

Given the trend toward the reduced role of the federal government, a dimished interest in civil rights, and a shift to the private sector, services and jobs for handicapped people may be made on an economic basis. Strategies, including the use of the purchasing power of disabled persons and the "job creation" aspects of architectural changes, may have been to be used to stimulate change.

-- L. ROBERT MC CONNELL

This paper raises a variety of issues for discussion. The minority status of disabled persons, and the diversity among disabled people, must be considered as we plan programs and policies for the future.

The author writes forcefully yet he writes from a biased viewpoint in that he fails to consider the available knowledge in relation to disabled persons and **older disabled persons.** In effect, I found the discussion of older persons to be biased with many negative stereotypes presented as accepted facts. It is unfortunate that a professional person or anyone for that matter, can write a paper that uses disabling language and disparages disabled individuals -- based on the arbitrary criterion of age. Is this congruent with rehabilitation philosophy?

Roth seems to assume that aging and "enfeeblement" are synonymous. The literature indicates otherwise. Only four percent of older persons are institutionalized, while another 10 percent need assistance in order to remain in their own homes. That leaves the vast majority of today's 24,000,000 older persons falling into some category other than enfeebled. Given that some 86 percent of all older persons have one or more chronic physical problems that limit their daily living activities, the obvious conclusion is that older people in general are excellent "copers" with their disabilities.

Roth indicates that the onset of "enfeeblement" is genetically programmed to begin in the 40's. It is difficult to respond to a statement so far-fetched as this one. There are virtually **no** life-span developmental theorists who even remotely refer to **middle-age in this fashion;** nor do any of the biological, psychological, or sociological theories of aging discuss middle-age from this perspective. Given this, Roth's statement that disabled persons -- presumably young adult disabled persons -- have little in common with older persons simply is **not true.**

-- JANE E. MYERS

Dr. Roth's far-ranging essay on the politics of disability and future trends offers many opportuniies to raise nettlesome questions about the status and future prospects of disabled people in the emerging high-tech world of bureaucracy. For the

sake of argument, I will side with the much maligned Malthus whose vision of what might happen if people keep on multiplying like rabbits was wrong in the short-run. On a world-scale, the verdict on the accuracy of Malthus' predictions cannot yet be pronounced; in the long-run his predictions may yet prove accurate.

In support of my contention, I offer the most recent World Development Reports (1982, 1983) of the World Bank which show a deteriorating state of affairs. The population of the 33 countries classified as "low income" and containing 47 percent of the world's total population is still growing. Their share of the gross world product has not changed in 25 years. And in many parts of the Third World, the per capita income has been falling since 1980. In addition, the debt that they owe to the richer nations has increased inexorably, compounded by the debt service they must pay out of their gross national product. With less and less left over for capitalization and improvements, these "disabled" nations have phantasized and even mouthed threats of defaulting on their debts unless the richer nations fork over still more loans to cover both new development projects and the debt service they owe on the old loans. Continuing loans are increasingly viewed as an entitlement -- perhaps even as a deserved "income transfer payment" from the rich to the poor nations. By banding together as a power block, these disadvantaged "minority" nations can wrest what they will from the richer nations under threat of economic terrorism.

Although the analogy may be somewhat strained at points, one can see similarities in the use of power politics by all disadvantaged groups. The developing nations, like the minority disability group in the United States and elsewhere, want the resources to develop their inherent capacities. They seek political organization to command a fairer share of available resources in order to develop these capacities. Once organized and powerful enough, there are all kinds of interesting possibilities for collective bargaining.

What are the legitimate goals of an organized disability power bloc? How far is the block willing to go in extracting what it believes is its due from the now dominant majority? These are limiting questions which ultimately determine whether it is better for the disabled to give up "a clinical status, a deserving poor status, a weak status." How far can disabled people push before feeling a backlash?

Dr. Roth speculates about the bureaucracy and how far it will go to accommodate disabled persons, both as clients and as workers. As a long-time bureaucrat, I am less sanguine than Dr. Roth in his easement of the possibilities for disabled people in public and private bureaucracies. I see little evidence that "people are able to be productive without domination, accountable out of responsibility rather than because of surveillance, actors in friendship rather than figures in hierarchy." Although thoughts such as these are soul-warming, the exploitative benefits of hierarchical arrangements and the maintenance of inequalties are just too tempting for public and private organizations to resist.

I am not sure I can agree with Dr. Roth that we are witnessing some new "legitimization of greed and the entrance of bigotry into polite conversation," "the ever increasing dismantling of affirmative action," and other accoutrements of the libertarian society. **Greed and bigotry have always been there.** The relevant question is how far the disability civil rights movement can go before risking backlash and retaliation?

This Switzer Seminar might well ask that question. Or is the possibility of backlash and retaliation too remote to take seriously?

-- JOHN H. NOBLE, JR.

I would like to address three points of focus in Dr. Roth's paper which were also mentioned in the paper by Dr. Noble, 1) the problem of limited available resources, 2) disincentives within bureaucracies and the need for what I refer to as independence incentives, and 3) the need to move beyond utilitarianism to more sophisticated ethical issues.

The problem of limited available resources is both real and vital and can be the basis for one of the strongest arguments of the disability rights movement. The effects of this reality are most readily seen on the local/individual level. When asked why Person A, who is dealing with a mental illness, can't get appropriate treatment while living at home, the response of the Mental Health/Mental Retardation agency is that there simply aren't enough funds to pay more community-based mental health workers. A look at this agency's budget shows 75 percent of its resources going to maintenance and expansion of a state-wide system of institutions and one percent going into community mental health services. Is this a question of limited resources or of priorities?

When asked why Person B, who uses a wheelchair and does not drive, can't get on the bus which stops on her street corner because it has no lift, and can't get half the trips she needs scheduled on the overstressed paratransit system, the response of the Transit Company is that there simply are't enough funds to expand the paratransit

system. A look at their decision-making process shows failure to adequately consider the long-term cost-benefit advantage of a fully accessible mainline system, and the long-term escalating expenditures and reduction of services inevitable in paratransit systems. Is this a question of limited resources or of failure to exercise good judgement?

The money is there. It is simply being spent, in too many cases on inefficient, ineffective, parternalistic services which have as their primary justification the preservation of the bureaucracy and antiquated concepts and not the quality of life of the individual. It behooves the disability rights movement, therefore, to focus its advocacy and education efforts on those who can influence **first draft budgetary decisions.**

Dr. Roth astutely points out the disincentives within the bureaucracy for individualized services which aim toward maximum productivity and quality of life. These must be replaced by independence incentives **for both the service provider and the individual.** This is best stated in Goal 11 of the National Policy for Persons with Disabilities which states:

"Disincentives to employment and to full social involvement shall be replaced by a comprehensive system of independence incentives and investiments in the productivity of persons with disabilities. Disabled people have a basic human right to receive services and benefits which enable them to fulfill their potential to participate productively and equally in the mainstream of society."

This concept seems to support the utilitarianism upon which Dr. Noble claims America is morally founded. Although Dr. Roth urges the movement to move on to more sophisticated ethical issues, I believe there is still quite a bit of work left to do to push utilitarianism to higher ground using more progressive, affirmative terms when applied to **disability.** In addition to pressing the more sophisticated ethical issues of morality and human rights, we must use the concepts and techniques of independent incentives and long-term cost-benefit and quality of life advantages to strengthen our advocacy.

-- MARGARET A. NOSEK

In the **medical, economic,** and the **socio-political** definitions of disability, as named by Hahn in another Chapter (4), the medical concepts continue to deserve serious consideration, even though socio-political concepts dominate the contemporary scene. The author, I believe, may not be aware that "enfeeblement" has not a valid medical implication; and especially when applied to old age (whose birth he states begins at age 40). The Center for Study of Aging and Human Development at Duke University has been in existence for almost 30 years. There it has been found that "enfeeblement" can be identified and prevented by early and effective medical management of its component parts, the same approach incidentally that brought us to the present progress in the field of the catastrophically disabled. To cite one example, the physical limping characteristic of "old age" can be prevented by proper posture and exercise twice dialy (much less time than for jogging) to compensate for the physiological loss of tissue between the vertebrae.

A second characteristic component of "enfeeblement" is psychophysiological (functional), the gradual and early substitution of new responsibilities to replace those inevitably removed by mandatory retirement. We need to place much more emphasised and research on the **prevention** of this syndrome, Alzheimer's Disease, that we have in the past. Granted the highly dubious anatomical and chemical cause-effect relationships in the presence of, but not proven as the cause of the late manifestations of Alzheimer's disease, leaves the individual only as a burden on society.

As recently as the 1940's a paraplegic's future was spoken as "half-dead." There may be a chemotherapeutic agent to support the psychological therapy mentioned above to prevent Alzheimer's. When his (or her) set of specific reactions changes as a result of the mere anticipation and environmental consensus preceding retirement, a new learning process and self discipline are essential. I also disagree with Frank Bowe's alliance at present between elderly and disabled persons; but also would refrain from a fixed attitude until the above clinical and psychological opportunities are thoroughly explored.

-- JAMES H. SEMANS

Dr. Roth's paper brings forth many points which warrant serious consideration in future decisions regarding the disability movement and rehabilitation. Dr. Roth's questioning of the utilitarian based cost-benefit analysis is a timely point. Is it possible that cost-benefit analysis is a tool which can ultimately be manipulated and controlled by those in power to perpetuate their system? Is it theoretically possible that the allocation of a dollar value to certain services or events and not to others creates a system predisposed to subjugation of persons with disabilities? What would happen to cost-benefit equations if dollar values were assigned for individual self-determination, individual self-esteem, and individual independence?

The notion of technology as empowerement coexisting with technology of domination appears feasible. There is no question that technology offers the potential for environments where the effects of disability are negated or minimized. Additionally, the awesome potential for technology in domination has begun to emerge in recent years.

It appears that this coexistence is more of a dynamic equilibrium. For a person with a disability, technology as the dominator could easily become a major force in exclusion of individual rights or subjugation in dead-end jobs. As an empowerer, technology could help persons with disabilities fit into an increasingly more bureaucratic society.

Perhaps the individual rights philosophy of the minority group model will temper this equilibrium in the direction of empowerment rather than exclusion. The bureaucracy of the state-federal VR system by its very legislative nature is a paradox. On the one hand it is a bureaucracy, on the other hand it has a philosophical and legal foundation on individual rights. Perhaps this paradox could begin to prepare the **state vocational rehabilitation counselor** for a role in maintaining the **empowering nature of technology** amidst bureaucratic tendencies for homogeneity and exclusion.

-- EDNA M. SZYMANSKI

The author in his analysis of the politics of disability and in his projection of what appear to him to be some likely future expectations, has identified a number of interrelated trends and factors; all most interesting, but some, in my opinion, crucial to the future direction and increasing momentum of the movement. One of the latter factors is the minority definition of disability which he describes as "of late fallen on hard times" like the other minorities. He argues convincingly however, concerning the gains that he expects to continue to accrue for the disabled people by virtue of this definition (in operation). He relates "the most remarkable successes..." attributable to this factor as "Section 504 of the Rehabilitation Act of 1973, the issuance of its regulations, and compliance..."

Probably one of the most substantive recent developments of potential broad scope and long term effects has been the self-advocacy groups and the coalitions formed and being formed with other groups. This development can lead to the political education of "disabled people in the use of the political process," potentially a powerful ingredient for successes in the movement. I agree that such groups and their activities require continuous nuturing since the personal reserves required for participation are so limited in a disabled population -- almost impossible if they are also poor. This type of activity should become an integral part of every comprehensive rehabilitation program.

The author brings the discussion to the issue of the nature of society itself, by several insightful observations and interesting questions on bureaucracy and people, particularly disabled persons and how one effects the other. He feels that the advances in high technology hold great promise for disabled individuals doing standard bureaucratic jobs in the future.

Finally, he emphasizes the potential great positive impact of high technology on the employment of those with disabilities through increased access to education and ultimately jobs.

Our own experience and that of similar populations remind us however, that certain aspects must be asssured such as adequate income, accessible housing and transportation in order that the potential benefits of high technology can be realized and shared among all eligiible clients. Deficiencies in any one or combination of these three could prohibit access to these great opportunities now and in the future.

-- HERBERT THORNHILL

Dr. Roth's paper appears to bring into perspective the issues raised by all of the authors. He, too, appears to accept a minority group model as the preferred "yellow brick road." However, he does stress the need for increased use of the political process. I would like to add that the increased sophistication of persons with disabilities in accessing this arena, need also to be realized by the persons to assist in providing services to persons with disabilities. There appears to be unfamiliarity with this area of "rehabilitation" among "workers" in the field. Perhaps this is brought about due to the fact that most vocational rehabilitation state agencies support with undying loyalty the 1920's paradigm, as described by Dr. Berkowitz in his paper. Further, there is no perceived incentive on the part of the rehabilitation counselor to widen his/her horizons by becoming an integral participating in the individual's realization of his/her goals beyond an adherence to the journey from Status 00-02 (referral/applicant) to Status 26 (successful rehabilitation). This is not to say, that the initiative or desire is not present. Rather, it is **not encouraged.** The actual contact with the "community of persons with disabilities" is negligible; steeped in numbers-crunching, paper processing and daily adaptation to "new" policies and procedures which may or may not have a semblance to the counselor's perception of what vocational rehabilitation is really about. Definitions become useful in direct relation to the prevailing political and fiscal climate.

The same question raised for me in reading Dr. Hahn's paper, surfaces again with Dr. Roth's, in the area of the compatibility of concepts. Must a rigid choice be made between paradigms? Is the problem that they are perceived as being in opposition, when in fact they may be catalytic? Hopefully, the recommendations presented by the Switzer Scholars answer the provocative issues raised by the authors and "reflections" proferred by the respondent scholars.

-- JANICE A. WOODWARD

Switzer Scholar Hahn

Chapter Four

Changing Perception of Disability and the Future of Rehabilitation

By Harlan Hahn

Although a capacity to change is the essential means of ensuring survival for any profession, the intensity of recent controversies in rehabilitation has provoked major questions about the future of the field. Evolving from a tradition which focused primarily on improving the skills of individuals with relatively minor disabilities to meet the demands of industry (E. Berkowitz, 1981), rehabilitation in the nineteen-seventies became embroiled in a debate about new objectives proposed by a growing social and political movement of disabled citizens. The Rehabilitation Act of 1973, for example, not only assigned a major priority to the needs of persons with severe disabilities; but it also defined discrimination as a critical problem facing disabled people. This reorientation poses both crucial challenges and a rare opportunity to develop innovative means of fulfilling the aspirations of Americans with disabilities. The purpose of this paper is to assess the impact of these trends on the future of rehabilitation.

The conflict which permeates this field not only seems to represent the divergent interests of professionals and disabled persons, but it also appears to reflect different theoretical orientations. Fundamentally, the present study and practice of rehabilitation seems to embody a struggle between competing paradigms (Hahn, 1984). The traditional approach, which might be termed the "functional limitations model," stresses methods of improving the physical and economic skills of disabled individuals to enable them to cope with the existing environment. By contrast, the new perspective, which may be called the "minority group" model, views the problems of disabled citizens primarily as a civil rights struggle issue which requires efforts to combat prejudice and discrimination (Hahn, 1984).

Perhaps much of the confusion about this controversy can be assigned to the different emphases which these concepts have received in prior research. While many earlier studies acknowledged that disabled persons could be regarded as a minority (Barker, et. al., 1953; Wright, 1960; Safilios-Rothschild, 1970, 114-115), or as a deprived and disadvantaged group (Gellman, 1959; Jordan, 1963), this notion did not become a central focus of investigations of disability until recently (Gliedman and Roth, 1980). The dominant interest in functional impairments appeared to preclude an examination of many topics that are crucial to a definitive evaluation of the "minority group" model (Hahn, 1984). Yet, important developments in rehabilitation such as the emergence of the disability rights and independent living movements indicated that the discipline was preparing to embark on a major shift in paradigms (DeJong, 1983). An analysis of critical differences between the opposing models in rehabilitation, therefore, seems essential to an assessment of future trends.

Competing Models of Disability

The distinctions that separate the two approaches embody contrasting definitions, units of analysis, assumptions, and goals. In many respects, an essential foundation for the emergence of the new paradigm was provided by a shift from a **medical** definition of disability, which focused on physical

impairments, to an **economic** perspective which emphasized vocational limitations, and finally to a **socio-political** orientation which regards disability as a product of the interaction between the individual and the environment (Hahn, 1982; Hahn, 1984; forthcoming). Whereas both the medical and economic definitions are basically compatible with the "functional limitations model," the socio-political understanding permits a recognition that the difficulties encountered by disabled persons may stem from their status as members of a minority group rather than from a loss of personal capabilities. Embedded in the socio-political approach is a realization that the definition of disability is fundamentally determined by public policy. In other words, disability is whatever laws and regulations say it is. Although government programs seem to contain an acknowledgement that a disability represents a disadvantage which requires remedial action (Hahn, 1985) forthcoming), the nature of the solution can only be determined by the quality of the evidence offered to support different conceptualizations of the problem. As a result, policymakers have an opportunity to choose between the divergent proposals implied by the two models.

The conflicting paradigms also encompass different views about the role of the individual and the environment in the determination of disability. The "functional limitations model" concentrates primarily on the individuals, but the "minority group" model focuses attention on external influences. From the latter perspective, the major problems associated with disability might be perceived as the consequence of a disabling environment rather than as a result of personal limitations. Unlike the clinical orientation which has guided conventional examinations of disability (Stubbins, 1982), the new approach allows an analysis of a variety of social and political forces which affect the lives of people with disabilities.

These discrepancies appear to reflect contrasting assumptions about the nature and meaning of disability. Although the conventional view seems to regard the existing environment as a "given" which is virtually fixed and immutable, for example, the new model recognizes that society can be altered by policy decisions to meet the needs of people with a wide range of disabilities. Similarly, the "functional limitations model" makes no attempt to identify the origins of the environmental barriers confronting disabled persons, but the "minority group" model traces this source primarily to the assumptions and values embedded in public policy. Hence, while the former approach seems to consider aversive perceptions of disability simply as another unfortunate burden which must be borne by disabled individuals, the latter perspective identifies discrimination as the fundamental source of their problems. In the development of the "minority group" model the task of separating the restrictive effects of discriminatory stereotypes from the environmental and functional restraints experienced by disabled persons is a crucial endeavor. This undertaking receives almost no attention from the "functional limitations model" which treats prejudical attitudes as a secondary or peripheral issue (Hahn, 1984; Hahn, 1985, forthcoming). The paradigms, therefore, are based on radically different theoretical premises which cannot be easily reconciled.

Perhaps even more fundamentally, the two models seem to imply alternative proposals for the solution of difficulties associated with disability. From the viewpoint of functional limitations, the prescribed remedy seems to focus almost exclusively on the development of further methods of improving the physical and occupational capabilities of the individual. Hence, enhanced testing procedures, expanded medical knowledge, and effective counseling techniques appear to comprise the principal objectives of rehabilitation professionals who have been trained in the traditional approach to disability. By contrast, the new perspective or the "minority group" model views the extension of civil rights as the primary means of resolving the problems of disabled citizens. Thus, principal attention is directed at the analysis of legal and policy issues which have a significant impact upon people with disabilities.

Efforts to develop laws and programs consistent with the interests of disabled persons required an extensive understanding of social and political influences that impinge on this segment of the population. Although the examination of public attitudes occupies a prominent position in the paradigm, this approach does not infer that bias and discrimination against disabled people can be eliminated by educational campaigns. Since prejudice is a deep-seated feeling of antipathy or aversion, other means of nullifying its effects are required. Perhaps the principal policy recommendation indicated by the "minority group" model is the rigorous enforcement of antidiscrimination designed to alter behavior toward citizens with disabilities. The ultimate goal of the new paradigm is the equal treatment of disabled persons in all aspects of social life.

The resolution of the conflict between these contrasting models involves more than academic interests. In a basic sense, there is a crucial relation-

ship between the conceptual frameworks that guide the analysis of an issue and perceptions of the general public and political leaders. Most lay persons regard disability primarily in the context of a feature story which chronicles the efforts of disabled individuals to overcome their adversities Both of these orientations are compatible with an emphasis on functional limitations. As a result, policy makers have had few opportunities to examine disability as an equal rights issue.

In a fundamental sense, however, the determination of the civil rights of citizens with disabilities seems to be an essential prerequisite to an assessment of functional capabilities. Until government policies delineate the legal rights of disabled persons to secure an environment appropriate to their needs, judgments about functional losses must be considered problematical rather than definitive. Hence, there is a pressing need to reverse or at least to revise the priorities that have traditionally been attached to the "functional limitations" and the "minority group" model in rehabilitation. Professionals can no longer afford to focus their attention solely on those aspects of a disabled person which signify a functional impairment. The stated goals of rehabilitation, which include developing the capacity to participate actively in the life of society, seem to reflect a major responsibility -- and an important opportunity -- to approach the needs of people with disabilities from a holistic perspective which includes an awareness of their rights as citizens.

Although critical differences separate the two models, they do not yet occupy an equivalent status in the field of rehabilitation. The preponderance of the research data collected on this subject thus far could be interpreted as supporting the traditional paradigm. There are obvious gaps in the empirical evidence needed to support further elaboration of the "minority group" perspective. Yet much of this discrepancy reflects historical circumstances. While the emphasis on functional limitations has guided investigations of disability for many years, interest in the problems confronting persons with disabilities as a minority group has become a significant object of attention only recently. Resources to support the study of issues indicated by the "minority group" model have not yet become available. Despite these considerations, significant patterns have emerged to indicate incipient changes in the theoretical orientations which have previously molded the study and practice of rehabilitation. In an era that has witnessed increasing demands by persons with disabilities for the right to control their own destiny, the issue of prejudice and discrimination cannot be neglected indefinitely. In order to preserve the support which they have customarily been given by persons with disabilities, rehabilitation professionals may be compelled to provide comparable backing for the goals espoused by the growing disability rights movement. Morevover, no occupation can perpetuate itself solely through a slavish adherence to ideas that have traditionally dictated its activities. Although the "functional limitations model" continues to dominate the field of rehabilitation, there are mounting signs that the new "minority group" model may have a crucial impact on its future.

These trends seem to provide the basis for a major reappraisal of rehabilitation . Many professionals who are accustomed to the conventional focus on functional impairments may have difficulty in grasping the concepts of the new paradigm and in applying these principles to their everyday activities. Perhaps even more importantly, there is a serious possibility that rehabilitation personnel are not preparing themselves for a future in which many of the problems presently associated with disability might be resolved through an extension of civil rights to disabled Americans. Clearly, in a nation that seeks to alleviate functional restrictions primarily through modifications of the environment and the rigid enforcement of laws against discrimination, rather than through continuous efforts to improve the functional capacities of the individual, the role of the rehabilitation counselor would reflect substantial changes. The goal might be perceived as visionary by some, but for others, the exciting prospects of such a world might be sufficient to persuade them to join the struggle to achieve this objective. This paper, therefore, seeks to assess developments which might occur in the field of rehabilitation as a result of increased acceptance of the new paradigm which identified the problem of citizens with disabilities as a civil rights issue. While the exploration is admittedly speculative, it is designed to provide a map of future terrain which may be quite different than the surroundings in which rehabilitation professionals currently find themselves. Although the accuracy of these predictions can only be determined from the marvelous perspective of hindsight, the importance of that task seems to justify the risks entailed in such an endeavor.

Changing Perceptions of Disability

Perhaps the most significant change which might result from increased acceptance of the "minority group" model is an extensive revision of prevailing assumption about biological capacities. Prior

research has often seemed to assume that the functional losses sustained by people with disabilities automatically relegate them to a position of inferiority in comparison with their nondisabled counterparts. By contrast, proponents of the new paradigm point out that presumptions of biological inferiority frequently have been employed to justify the subordination of other minorities. The subjugation of black citizens and ethnic groups, for example, was rationalized by arguments that this disadvantaged status could be attributed to alleged genetic deficiencies; and the supposed weakness or frailty of women somethimes was offered as an excuse to deny them employment and other opportunities. Moreover, this oppression sometimes was disguised as an attempt to protect deprived groups from the harm or failure which they might suffer if they should aspire to positions of influence commensurate with the privileges enjoyed by the dominant majority. The assumption that the problems of the persons with disabilities stem primarily from their inferior functional capabilities appears to neglect the awesome adaptability which they have displayed in coping with obstacles that they encounter in their everyday lives. Yet the physical demands imposed upon people with disabilities by the existing environment do seem to force them into a position of inequality in relation to the nondisabled majority. The effort to remove the taint of inferiority from persons with disabilities appears to depend on two additional assumptions which have usually been ignored in prior analysis of this subject.

Initially, the extent to which biological inferiority is viewed as an unfortunate but unavoidable consequence of disability, or as an unwarranted label that has been applied to persons with disabilities, may be determined by the capacity to imagine a different type of environment. Many persons seem to assume that the stairs they climb, the distance they walk, the materials they read, and the messages they hear are virtually decreed by natural law. They might find it difficult to envision a world which would impose fewer demands and less strain on their bodies. Others, however, have begun to consider methods of restructuring the environment according to a concept of "universal design", which seeks to create surroundings compatible with a broad range of human capabilities, or principle of "individuations," which implies a society designed to meet the needs of each of its members (Hahn, 1985, forthcoming). There appears to be a growing recognition that mastery of the present environment, which was designed almost exclusively for the nondisabled, is not an appropriate requirement for the opportunity to engage in many activities that are considered the inherent right of all citizens. As increased progress is made in planning an environment to accommodate the desires of persons with disabilities, pervasive assumptions about the supposed biological limitations of this segment of the population obviously must be eliminated.

A second condition for reversing the presumption that citizens with disabilities are biologically inferior to their nondisabled peers is the realization that the environment is fundamentally shaped by public policy. The current configurations of manmade structures which pose seemingly insurmountable problems for many persons with disabilities, as an example, basically exist because statutes, ordinances, codes, and regulations allowed them to be constructed in that manner. This awareness also facilitates an examination of the extent to which the architectural and institutional barriers confronting persons with disabilities are not accidental or coincidental. Implicit in government policies are expectations, values, and attitudes about the personal capabilities which human beings ought to possess in order to be accepted as participating members of the community. Thus policy-makers must devote serious attention to the possibility that features of the environment which have an adverse effect on persons with disabilities may reflect a pervasive, deep-seated aversion to these people. As policies are increasingly changed to produce an environemnt which would permit citizens with disabilities to be treated in an impartial manner, many prevailing myths about the alleged biological inferiority of persons with disabilities are almost certain to be eradicated.

The mounting recognition that citizens with disabilities comprise a minority in American society also is likely to create an increased consciousness of the serious discrepancies between the status of this group and democratic values such as freedom and equality. Most disabled Americans live in an architectural and organizational environment which denies them significant personal choice and individual autonomy. Ironically, for example, while "freedom of movement" is constitutionally guaranteed to international travelers, the same right is not extended to persons who use wheelchairs in their own neighborhoods and communities. Similarly, people with a variety of disabilities have been compelled to demonstate their talent in surroundings which deprive them of "equality of opportunity" and even the prospect of achieving parity with their nondisabled competitiors. The tension between the everyday problems encountered by disabled Americans and concepts of liberty and

equality cannot be sustained indefinitely. As the new perspective on civil rights gradually begins to supplant the "functional limitations" model as a primary basis for understanding disability, increasing demands may emerge for policy changes to extend the promise of freedom and equality to persons with disabilities.

Perhaps the most intense controversy about the "minority group" paradigm, however, is apt to develop around the assessment of public attitudes concerning disability. Many nondisabled observes, for example, might be prepared to admit that the effects of impairments can be significantly reduced by modifying the environment to fit the needs of disabled persons and that legal and political changes are necessary to grant them liberty and equality; but there appears to be a widespread reluctance to agree that the primary problems associated with a disability derive from the prejudice and discrimination of others rather than from their own functional limitations. Perhaps this reticence may reflect the unwillingness of the nondisabled majority to acknowledge its own complicity in the plight of persons with disabilities. In any event, a similar pattern seems to be evident in research on this subject. Although there is widespread acceptance in rehabilitation literature that disabled individuals often become the victims of stigma, for example, these studies devote surprisingly little attention to the process of stereotyping. This tendency seems ironic. Whereas Goffman (1963: 5) defined stigmatized person as someone who is perceived as "not quite human," Allport (1958: 87) describes a stereotype as "an exaggerated belief associated with a category." In many respects, stigma might be interpreted as a more powerful and destructive form of prejudice than stereotyping; but neither concept has been used effectively in appraising discrimination against persons with disabilities.

The intensive examination of stereotypes of disability seems crucial to gaining increased acceptance of the "minority group" model. Although available data are admittedly insufficient as yet to confirm their suspicions definitively, the experience of many persons with disabilities strongly suggests that a major problem in securing jobs is the difficulty which employers have in evaluating their physical or behavioral capabilities. A disability that becomes evident in a job interview or application often is perceived as prima facie evidence that the disabled applicant could not do the tasks required by the work. Employers who are unfamiliar with disability may naturally tend to underestimate the capacities of persons with disabilities, and they might even fail to realize that their assessments represent exaggerated or stereotypical thinking about disability. Moreover, personnel officers usually are not trained to consider ways in which the worksite or the job could be modified to fit the aptitudes of a disability employee. As a result, the existence of a disability often is used as a means of discounting or disqualifying an individual who must compete with nondisabled as applicants. Unfortunately, disabled job seekers who are most familiar with their own capabilities usually are not in a position to refute their employer's presumption that they would be unable to perform the work successfully. While some of these decisions may reflect a balanced but unfavorable judgment about the capabilities of persons with disabilities, others undoubtedly are based on stereotypes of disability. The difficulty of separating valid generalizations from stereotypical perceptions is obviously a complicated endeavor. Yet research which neglects important concepts such as stereotyping has prevented the field of rehabilitation from responding effectively to this critical change. As additional information is gathered about stereotypes of disability, significant changes in the study and practice of rehabilitation can be anticipated.

One method of assessing the impact of prejudice upon persons with disabilities -- and of clarifying the definition of disability -- entails the construction of a "disability continuum," which permits on examination of the association between the visibility of a disability and the amount of discrimination directed at persons with disabilities (Hahn, 1984, forthcoming). From this perspective, functional restrictions may have a less significant effect on the experiences of persons with disabilities than the extent to which a disability is immediately obvious or detectable through close careful scrutiny. Disability thus exists primarily in the eye of the beholder. Although unfavorable reactions to a permanent disability may be evoked by written descriptions as well as by personal observations, this approach provides a means not only of reconceptualizing the study of this subject by also of exploring the so-called attitudinal environment of society. Clearly if the hypothesized relationship between discrimination and the appearance of disability is confirmed by empirical research, this finding would provide significant support for the "minority group" model. While the previous preoccupation with functional limitations has appeared to preclude a serious investigation of this research design, their appears to be no intrinsic reason to dismiss the expectation that discrimination may be related to the visibility of deviant physical characteristics such as a disability. Disabled people seem to share many problems

with other disadvantaged groups which are identified by traits such as skin, color, gender, or age. These attributes allow persons who become the targets of prejudice to be differentiated from the remainder of the population and they permit the perpetuation of a relationship of subordination and dominance between deprived minorities and the entrenched majority. As futher evidence is collected about the effects of relatively visible disabilities upon human perceptions, important evidence that discrimination is the major problem facing persons with disabilities might be anticipated.

There are several methods of assessing the extent to which designation as a minority group can be applied to any segment of the population. Perhaps the most persuasive arguments are based on an examination of their status in society. By this criterion, the conclusion that persons with disabilities for a minority group seems almost inescapable. Although available statistics are seriously marred persons with disabilities probably experience the highest unemployment rates and the most extensive levels of welfare dependency in the country. In comparison with other minorities, they may also compromise the largest proportion of people living in poverty. Disabled citizens have been subjected to rigid patterns of separation or segregation in education and social institutions. Morevover, they have been prevented by architectural barriers and other features of the environment from securing equal treatment in housing, transportation, and public accommodations (Hahn, 1983). On almost every issue which has emerged in earlier investigations of prejudice and discrimination, the analogy between the subjugated status of persons with disabilities and the plight of commonly recognized social, ethnic, and other minorities seems clear and convincing. Yet, since much of the data could be interpreted as a product of functional limitations in an environment which is not adapted to the needs of persons with disabilities, there has been relatively little popular or professional recognition of the minority status of persons with disabilities. Increased acceptance of the new perspective on the study of disability, therefore, may depend on additional considerations.

Another important means of examing persons with disabilities as a minority group involves an investigation of the sources of their subserviant role in society. Although alternative interpretations focusing on broad historical forces also have been proposed to explain the disadvantaged position of disabled Americans, a major portion of this approach entails the analysis of public attitudes. To qualify for consideration as a minority group, data apparently must be offered to prove that disabled citizens not only have been the victims of social and economic deprevation but also to demonstrate that their disadvantaged status can be ascribed to prejudicial attitudes. Ultimate approval of the"minority group" perspective may be contingent on evidence of antipathy or malevolence toward persons with disabilities. The disadvantages encountered by this group must be traced to bias or prejudice rather than to functional limitations. Without such empirical findings, charges of discrimination against persons with disabilities could be readily dismissed or disregarded.

Unfortunately, the investigation of prejudice toward persons with disabilities is an exceedingly difficult task in a society which places a high premium not only on functional abilities but also on conventional standards of physical appearance. A pervasive atmosphere of sympathy and paternalism makes it hard for the nondisabled to admit that they may harbor deep-seated feelings of avoidance concerning persons with disabilities whom they also perceive as the victims of misfortune. In addition, previous research on attitudes about disability, which has tended to focus on diagnostic categories rather than on the effects of visibility or labeling, was not guided by a theoretical orientation that permitted a thorough examination of prejudice. Although a literature review revealed that unfavorable attitudes toward persons with disabilities were related to antagonistic perceptions of other minorities (English, 1977), the data usually have not been considered sufficient to support the contention that prejudice is a primary source of the problems confronting people with disabilities. Yet available studies provide significant evidence indicating not only the existence of aversion toward persons with disabilities but also the presence of "existential" and "aesthetic" anxieties which may be triggered by perceptions of disability (Hahn, 1983). The nondisabled tend to project their own fears about the debilitating effects of a disability on disabled individuals and to reveal an observable distaste for persons whose appearance reflects a marked departure from conventional images of the human form. Although additional research obviously is needed to explore many dimensions of public attitudes toward disability, the forms of aversion which may have been discovered thus far indicate that the origins of the problems facing persons with disabilities can be traced to the prejudicial sentiments of the nondisabled majority. Overt displays of bigotry are not essential to the identification of a minority group which requires legal protection in order to exercise human rights. In fact,

in many respects, relatively subtle forms of bias and prejudice may be even more insidious and difficult to eradicate than unconcealed manifestations of intolerance. As increased information is discovered about nondisabled perceptions of persons with disabilities, the traditiional preeminence enjoyed by the "functional limitations" model may be gradually supplanted by a growing conern about the civil rights of this segment of the population.

The experience of persons with disabilities has seemd to parallel the difficulties encountered by other minority groups. The problems include assumptions of biological inferiority, the denial of constitutional guarantees of freedom and equality, segregation, stigmatizing, stereotyping, bias, and prejudice. The cumulative impact of the evidence, therefore, supports the conclusion that discrimination is the underlying issue affecting citizens with disabilities. While additional research clearly is needed to specify the extent to which prejudice is responsible for the environmental obstacles encountered by persons with disabilities, the basic features of the "minority group" model appear to be amply confirmed by available information. Discrimination cannot be disregarded as a fundamental factor shaping the treatment of persons with disabilities. Yet, policy-makers, professionals and the general public must be persuaded that this analysis represents a more satisfactory explanation of the problems of persons with disabilities than the implications of the "functional limitations" paradigm. Although scholarly investigations may play a crucial role in this endeavor, perhaps a major obligation in fulfilling this objective also must be assumed by persons with disabilities themselves.

The Emergence of a Minority Group

In addition to examinations of the origins and consequences of discrimination, there is another important means by which a group can achieve recognition as a minority. Segments of the population often gain this designation by displaying a willingness to identify themselves in this way. The importance of self-identification as a standard for defining a disadvantaged group raises critical issues for people with disabilities. In recent years, the disability rights movement has gained growing popularity among persons with disabilities in large measure because of its willingness to embrace the "minority group" model. There seems to be little doubt that, to a greater extent than professionals, policy-makers, or the nondisabled majority, persons with disabilities are prepared to define prejudice and discrimination as their major problems.

But the effort to convince others of the accuracy of their analysis requires disabled individuals to identify primarily with that aspect of themselves which is most negatively stigmatized by the remainder of society and to organize and mobilize politically around it. This is an imposing but unavoidable demand. The outcome of major conflicts over policy issues is decided not only by the theoretical orientations which guide research on the subject, but it is also shaped by the political resources which various groups are able to exert on behalf of different solutions to the problem. As a result, serious attention must be devoted to attempts by the disabled minorty to develop a cohesive influence on policy issues.

In many respects, the potential strength of disabled citizens appears to be vast. Although existing statistics are flawed by definitional inadequacies, persons with disabilities could be considered the largest minority in the United States. According to the most widely quoted estimates, the size of this segment of the population is approximately 36 million (Bowe, 1978, 1980). Yet, persons with disabilities have not been able to organize a political constituency comparable to the power of other minorities. Much of this failure can be attributed to the impact of a medical model that encourages both nondisabled and disabled observers to focus their attention on separate diagnostic categories rather than on the generic characteristics of disability. As a result, the disabled minority tends to be fragmented and disunited.

Increasing acceptance of their "minority group" model which emphasizes prejudice and discrimination, however, provides a means of resolving this difficulty. From a perspective that stresses the reactions evoked by visible or identifiable disabilities rather than personal limitations, persons with disabilities might be able to recognize the similar experiences which unite them rather than the functional differences which divide them. Although there appears to be vast discrepancies between the worker with low back pain and persons who are blind, deaf, or in wheelchairs, for example, all of them possess detectable disabilities which often make them the victims of stereotypical perceptions. Moreover, the stereotypes that frequently prevent persons with disabilities from securing employment may reflect a deep-seated aversion rather than sheer ignorance. To the extent that people with various types of disabilities can begin to realize that their problems stem from prejudice and discrimination rather than from functional limitations, they may develop a sense of cohesion that could provide the foundation for a powerful and growing political movement. These trends have far-reaching exten-

sive implications for the study and practice of rehabilitation.

There are, however, other difficulties which reduce the capacity or ability of disabled Americans to act as a unified minority. Unlike most similar groups, membership in the disabled community usually is not determined at birth. In general, individuals with disabilities are raised for the transition to this role. There is a lack of generational continuity among persons with disabilities that prevents them from perpetuating a legacy which might otherwise be an important refuge. In addition, persons with disabilities, after they leave hospitals or rehabilitation facilities, usually are geographically dispersed in an environment which limits their opportunities to maintain contact with each other. This sense of isolation, which is often compounded by architectural barriers and transportation or communication difficulties, undoubtedly is a major factor contributing to the relative absence of cohesion among persons with disabilities. Perhaps even more significantly, men and women with disabilities often lack a strong sense of collective identity which might become a reference point for their quest for equal rights. Nondisabled professionals have promoted the belief that a disability is an individual limitation to be "overcome" rather than a foundation for social and political strivings. Most citizens with disabilities have experienced the effects of bias, prejudice and discrimination in their own lives, but these incidents often are interpreted as a symbol of their vulnerability rather than as an impetus for political organization.

Perhaps one of the most crucial needs of the disability rights movement is the development of a positive sense of identity among persons with disabilities. In many respects the social and political movement of persons with disabilities represents what Anspach (1979) has termed a form of "identity" politics in which activism is displayed primarily by those individuals with disabilities who have succeeded in developing a positive image of themselves and a somewhat relatively problematic or skeptical view of society. Unfortunately, this orientation is not facilitated by the implications of the "functional limitations" model that often encourage persons with disabilities to be grateful for minor modifications of the environment and that frequently considers self-image to be a difficult issue for people who are presumed to be physically inferior to their nondisabled counterparts. The identification of bias and discrimination as an external problem of the nondisabled majority rather than as a force which must be internalized by the disabled individual can be an important antidote for self-deprecating sentiments among persons with disabilities, but these experiences do not necessarily form a solid foundation for the advancement of a social and political movement which seeks a comprehensive redefinition of the nature and meaning of disability. In a fundamental sense, the continued progress of this movement may depend on the emergence of a phenomenon similar to the "black-is-beautiful" phase of the civil rights revolution of the 1960s.

Citizens with disabilities must acquire a sense of dignity and pride which will enable them to pursue their struggles for equal rights in an atmosphere permeated by aversion and other external restrictions. The challenge represents an imposing responsibility, and it also provides rehabilitation personnel with a critical opportunity to gain an increased understanding of the values and perspectives which are shared by the disabled minority.

Although persons with disabilities often are perceived primarily as deserving recipients of help, there are many important roles which they can play in providing assistance to nondisabled professionals. In fact, the common experiences described by persons with disabilities in numerous meetings indicate the possible existence of a disability subculture which could be a valuable resource for developing innovative means of resolving the difficulties encountered by this group. Although these cultural values cannot be enumerated specifically until detailed empirical reserach is conducted on this subject, many of these experiences seem to embody positive as well as negative aspects of understandings derived from the experience of anger and injustice that are commonly exhibited by victims of discrimination, but they also have exhibited an adaptability in coping with environmental obstacles which appears to rival or surpass the capacities of their nondisabled counter-parts. Through careful planning and the display of awesome ingenuity in devising methods of circumventing barriers which they encounter in their everyday lives, persons with disabilities have gained a tenacity of resilience that might be a critical source of strength in prolonged political struggles. Fundamentally, a disability seems to signify the superficiality of physical standards in modern society. Many persons with disabilities do not appear to meet the prescribed norms of appearance, attractiveness, agility, or prowess which this culture has established as a precondition for active participation in the affairs of the community. And yet they have survived. Their presence seems to bear unspoken testimony to irrelevance of the functional capabilities which are presumed to be necessary for human beings in this

civilization. Through an enhanced awareness of the values to be discovered in the previously unidentified subculture, an important basis could be established for recognizing their contribution to the richness and diversity of the social order.

The two competing models which evolved in research on disability have seemed to yield distinctive emphases on "service delivery" or "disability rights" as the primary solutions to the problems of this segment of the population. These differences also appear to represent contrasting estimates of the potential for environmental change. Whereas the "functional limitations" perspective views the provision of extensive services as the most appropriate means of assisting persons with disabilities in surroundings which cannot or will not be adapted to satisfy their needs and desires, proponents of the "minority group" orientation paradigm refuse to abandon the prospect of a world in which these modifications are treated as a right rather than as a privilege or a special concession. Obviously, until these alterations are made, the need for a broad range of social services must be given a high priority. Yet the vision of a society in which environmental adaptations will be viewed as a part of a basic commitment to values such as freedom and equality must not be sacrificed to an inordinate concern with meeting the immediate functional requirements of persons with disabilities in the existing environment. Programs and policies which regard the delivery of services as the sole, exclusive or principal means of aiding disabled individuals may ultimately prove to be incomplete and even self-defeating.

Perhaps the clearest example of the tension between proposals for "service delivery" and "disability rights" can be found in the current status of the principle of independent living. Although this concept was originally conceived by nondisabled professionals as an alternative for individuals with severe disabilities who were not considered feasible candidates for employment, the independent living movement emerged rapidly among persons with disabilities as a means of developing a supporting community as the foundation for noninstitutionalized life. In their initial years, centers for independent living developed projects such as advocacy and peer counseling which seemed to reflect the indiginous values of the disabled portion of the population. Subsequently, however, there has been increasing pressure to curtail these programs and to concentrate on other activities such as attendant care, housing referrals, and transportation which seemed more consistent with traditional modes of service delivery. Most of the latter activities focus on indivudal needs rather than on the collective interest of persons with disabilities or on efforts to alter the environment. As independent living centers become increasingly dependent on public as well as private sources of funding, there is a serious danger that mounting attempts will be made to eliminate projects which serve the common interests of persons with disabilities as a minority group and to provide exclusive support for policies that are developed as a remedy for the functional limitations of individuals.

The dilemma is not unique to the disability community. Many programs are implicitly organized to satisfy the concerns of adminstrators or service providers rather than the clients whom they are supposed to serve. But the paradox is exacerbated for disabled people by the strong possibility that the shared values of this minority also encompass a problematic view of medical and other forms of professional authority. Thus, to the extent that independent living projects depart from self-help modes or programs implied by the mutual experiences of persons with disabilities, here is a major threat that they may lose the support of their clients. A similar risk might eventually become evident in the disability rights movement. Although extensive litigation is needed to expand the civil rights of persons with disabilities, the future of this group cannot depend solely on legal expertise. Perhaps just as important as the continuation of social services and the protection of legal rights is the investigation of the mutal values and experiences which join citizens. From the perspective of the "functional limitations" model which proposed improvements in individual capabilities and the provision of needed services as the principal solutions to the problems of persons with disabilities, there seemed to be little reason to consult persons with disabilities or to seek their assistance in the design of policies and programs affecting this group. By contrast, the "minority group" paradigm, which implies the need for a massive restructuring of the environment, provides a foundation for gathering essential information not only about the detrimental effects of prejudice and discrimination but also about the rich insights which persons with disabilities might contribute to the remainder of society.

Policy Implications

Perhaps the most obvious implications of the "minority group" paradigm for the future of rehabilitation are evident in the areas of research and training. There is a growing need to provide support for the study of issues indicated by the new perspective which is equivalent or at least propor-

tionate to the resources dedicated to the investigation of propositions suggested by the "functional limitations" model. Similarly, students preparing for careers in rehabilitation and related professions must receive information about policies that affect the civil rights of persons with disabilities as well as nondisabled experts. Just as a national institute for the study of problems facing women would not be expected to allocate most of its resources to males, for example, comparable questions might be raised about the relative neglect off the perspectives of persons with disabilities in the conduct of research on rehabilitation. An organization of persons with disabilities in a wide range of academic disciplines, known as the Disability Forum, currently is forming to reexamine research priorities and to develop new policy proposals in this field. In addition, institutions of higher education such as the University of Southern California are beginning to form multi-disciplinary curricula that focus on the common experiences shared by disabled people, the analysis of disability policy and the examination of civil rights issues to augment the instruction received by students in rehabilitation and similar departments preparing students for occupations which commit them to serve the interests and needs of persons with disabilities.

Although the "functional limitations" model continues to dominate rehabilitation and related fields, intensified efforts to examine the major propositions of the alternative paradigm could provide valuable contributions to these professions. Initially, of course, the increased investigation of the principal elements of the "minority group" perspective comprises an empirical means of verifying or rejecting this approach. If functional restrictions play a greater role in the problems of persons with disabilities than aversive attitudes, continued emphasis on the former concept in research on disability would gain additional justification; but, if prejudicial perceptions are found to be a fundamental source of the difficulties encountered by persons with disabilities, there would seem to be a pressing need to reconceptualize the issue. Perhaps more importantly, the analysis of citizens with disabilities as a minority group in contemporary society offers an opportunity to revitalize and enrich the study of rehabilitation. While conflict is usually an integral aspect of the process of change, defenders of the traditional paradigm in the study of disability might want to consider the potential advantages which a corresponding emphasis on investigations or the new theoretical framework could contribute to the future development of this field.

The increased acceptance of the "minority group" concept also seems to provide a means of resolving the definitional confusion which has surrounded the development of programs affecting persons with disabilities. Much of the acknowledged lack of coherence in federal disability policy, for example, can be attributed to the inadequacy of current definitions. While some governmental programs define disability as an inability to perform one or more of several major life activities, others measure reductions in functional capacities produced by different impairments. Perhaps the most destructive definition is the provision in social-welfare laws legislation concerning an inability to engage in "substantial gainful activity," which appears to equate disability and unemployability.

As a result, many adults with disabilities who cannot find employment due to discrimination or other causes frequently are compelled to prove that they are unable to perform "substantial gainful activity" in order to qualify for resources which they need to sustain themselves; and, after they have been officially labeled as unemployable, they are encouraged by another government agency to participate actively in rehabilitation efforts so that they can return to the labor force. Moreover, regulations in many states which restrict rehabilitation training to "entry-level" jobs essentially tell disabled clients that, after they have acquired a disability, they must assume the additional burden of starting their vocational lives over again. Thus, they are not allowed to develop skills which could qualify them for supervisory, managerial, or professional positions that would be more compatible with their functional capacities in surroundings designed for the nondisabled. Medical and economic definitions of disability, which are based on the concept of functional limitations, also appear to reflect the assumptions of an economy based on manual labor rather than on the delivery of services or on sophisticated technology. In addition, these definitions divert attention from possible alterations in the environment including methods of modifying the job or the worksite to accommodate the needs of disabled employees. Prevalent understandings of disability are almost certain to change as a result of expanding technology, policy decisions, and increased knowledge of the experiences of persons with disabilities. There is a mounting demand in the disability community for policies designed to adapt external surroundings to meet the needs and desires of citizens with disabilities as a replacement for prior programs which have compelled them to fit the requirements of the existing environment. Thus, definitions based on the "functional limitations" model may be an inappropriate foundation for the

formulation of policy and for the practice of rehabilitation in the future.

In contrast to the restrictive assumptions encapsulated in the "functional limitations" model, the major premises of the "minority group" perspective provide a potential means of attacking the problem of disability at its source. This approach is founded on a "socio-political" definition which views disability as the product of the interaction between the environment and the individual. An especially crucial component of the environment consists of the attitudes and perceptions of the nondisabled majority. From this vantage point, the restrictions imposed on citizens with disabilities by the architectural and institutional environment cannnot be considered accidental or coincidental; they are produced by public policies which embody values and attitudes that include aversive feelings about persons with identifiable disabilities. As a result, the constraints inflicted on this group also may be interpreted as reflecting an unwarranted and unconscionable denial of freedom and equality. To test the implications of this theoretical orientation, effects of the visibility of permanent disabilities could be assessed by examing the relationship between discrimination and disabilities which are either immediately obvious, detectable through careful scrutiny, or identified through other processes such as labeling. This approach emphasizes the discriminatory consequences of perceptions and stereotypes of disability. Although the traditional dominance of the "functional limitations" model has prevented the accumulation of sufficient evidence to support all aspects of the new paradigm, the allocation of additional resources to examine this alternative is not only amply justified by available data, but it also permits an investigation of civil rights issues which is virtually precluded by the earlier orientation.

This stress on bias, stereotypes, and discrimination which prevents the equal treatment of citizens with disabilities obviously has significant implications for vocational rehabilitation. Serious analyses must be conducted, for example, to determine the appropriateness of functional requirements and physical examinations which have been established as preconditions for many types of jobs. While some of these prerequisites might appear to be justified by the demands exerted on human beings by the configurations of the existing environment, others may reflect stereotypical perceptions of disability or an unwillingness to modify the job or the worksite to fit the capabilities of workers with disabilities. Perhaps the clearest evidence of the irrelevance of functional requirements to employment was provided by experience during World War II when, in the face of severe labor shortages, the stipulations were waived to permit the hiring of workers with disabilities and other minorities who lost their jobs after the war when the requirements were reimposed to facilitate the employment of nondisabled veterans. The rehabilitation profession might play a critical role in evaluating the discriminatory impact of functional requirements and physical exams to prevent these inequities from occurring again. Similarly, assessments must be undertaken to determine the effects of insurance programs on the equal treatment of disabled employees. Although federally assisted corporations are prohibited from discriminating against disabled job applicants, comparable laws have not been enacted to prevent the insurance industry from increasing premiums of compamies that hire disabled personnel.

While the appraisal of this problem could lead investigators into the murky world of actuarial tables and complex statistical calculations, insurance practices may reflect a serious misunderstanding of the nature of disability which has had a restricting impact on the opportunities available to citizens with disabilities. Finally, the analysis of the problems of disability Americans as a minority group indicates the need for increased studies of the attitudes of employers. There is little reason to believe that they are immune from the same feelings of aversion about disabled persons found in the general population. Nor may they be capable of judging the qualifications of disabled job seekers as nondisabled competitors. Efforts also might be taken to ensure that the relative neglect of these issues has not been promoted by the delicate relationship between rehabilitation professionals and employers or their dependence on businesses to secure the successful placement of clients with disabilities.

Perhaps the most important change in the role of rehabilitation professionals implied by the "minority group" model, however, is their increased involvement in monitoring, implementing, and enforcing antidiscrimination laws. At the present time, there appears to be little or no connection between the efforts of rehabilitation personnel to find employment for citizens with disabilities and attempts to secure compliance with laws prohibiting discrimination against this group. This distinction not only seems artificial, but it also appears to subvert the enforcement of measures prohibiting bias in the hiring of persons with disabilities. Moreover, if further research were to demonstrate that prejudice and discrimination are the basic prin-

cipal problems facing citizens with disabilities, the duties of rehabilitation professionals may need to shift accordingly. At least, the objectives of rehabilitation counselors must change from an almost exclusive concern with the supply of workers with disabilities to a corresponding interest in the demand side of the hiring equation. Other measures such as rigorously enforced employment quotas, a comprehensive public program of medical care, and an allowance to offset the additional costs of a disability also might be considered as means of gaining increased equality for employed as well a unemployed citizens with disabilities. Fundamentally, the principal objectives of persons with disabilities reflect a demand for environmental changes which would allow them to receive fair and impartial treatment not only in employment but also in deduction, housing, transportation, public accommodations, and other areas of social life.

Although the "minority group" model seems to identify aversive attitudes as the primary problem confronting persons with disabilities, it does not imply that these sentiments can be changed by public education or rational persuasion. On the contrary, reliance on the strict enforcement of antidiscrimination laws as the principal policy recommendation also reflect a belief that effort to alter behavior must precede attempts to modify attitudes. Perhaps one of the most serious mistakes made by social analysis is the tendency to underestimate the adaptability of human beings. Under the constraint of legal requirement, many people have learned to tolerate and even to approve of others whom they previously regarded as totally unworthy and unacceptable. Other evidence suggests that the most effective means of transforming prejudicial attitudes of the dominant majority toward a disadvantaged minority is by promoting increased contacts between members of the two groups at equivalent levels of social and economic status. In the past, aversive feelings about people with visible or identifiable disabilities undoubtedly have been exacerbated not only by socio-economic deprivations but also by environmental obstacles which preclude extensive encounters between this group and the nondisabled majority. The movement to extend the civil rights of persons with disabilities, therefore, may represent the ultimate test of the human capacity to change attitudes and behavior. The pursuit of this objective seems to form a crucial challenge facing modern civilization. Rehabilitation personnel have an unusual opportunity to join with citizens with disabilities in the quest for this goal.

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Excerpts of Reviews and Comments

The following are excerpts of reviews, comments, questions and recommendations made by the Switzer Scholars. These are presented to further stimulate thinking, discussion and action as it relates to the content of Chapter Four by Harlan Hahn.

The debate over approriate models of disability will continue as long as rehabilitation remains dynamic. Hahn views a healthy profession as one that welcomes change which is a result of the consistent reassessment of the profession's attitudes, values and beliefs. It seems to me that this is essentially an extension of the society in general, or environment that the professions identify as their frame of reference. Further, this approach exemplifies what the tenets of the rehabilitation philosophy and subsequent programs are built upon.

We must not lose sight of what I consider to be the crux of the movement assisting a human being to move gradually, in some manner, away from a "dependence" to a degree of "independence." The measurement or quantitative aspect is secondary to the qualitative element or the process, defined as movement. In addition, movement equates with "change" or "dynamism." We cannot expect disabled persons to accept these concepts if we as a profession continue to accept dependence from external sources; i.e. (government, policy-makers, funding sources, etc.).

The models of disability provided by Hahn are excellent; we must continue to focus on advancement toward operationalization and not simply be satisfied with "theoretical constructs." We as professionals must also retain a sense of realism when assessing what is within our control when it comes to educating or reeducating a society.

Attitudes, values, and beliefs cannot be legislated; however, role models can be helpful in shaping values toward accepting and implementing a shift in what is expected by one's professional society or the larger society, of which we are all members.
-- WILLIAM A. CALZARETTA

Harlan Hahn describes the field of rehabilitation as one that is permeated by conflict "which ... not only seems to represent the divergent interests of professionals and disabled persons, but (which) ... also appears to reflect (their) different theoretical orientations." Dr. Hahn then puts forth a convincing argument that while rehabilitation professionals have almost exclusively been invested in the further development of traditional programs in the functional limitations model, disabled leaders and their allies have evolved the "minority group model" wherein the problems of disabled citizens are viewed as a civil rights struggle which requires efforts to combat prejudice and discrimination. He predicts that the potential for tension, controversy and conflict between proponents of the two models will increase unless public policy-makers and professional rehabilitation leaders devote substantially more study to the "minority group model" as one means of "preparing themselves for a future in which many of the problems presently associated with disability might be resolved through an extension of civil rights to disabled Americans." Dr. Hahn also describes several other measures which should be undertaken to support the disability rights movement as one of comparable importance to the evolution of traditional programs.

Regardless of the extent to which one agrees with Dr. Hahn's views on the trends and forces which interact in our rehabilitation environment, and in the broader socio-political environment, one must acknowledge that public policy-makers and rehabilitation leaders have been slow to incorporate the views of disabled persons in the political processes that have profound impact on the lives of disabled people. Oh yes, there are many constraints. Disability and rehabilitation policy is made in the public sectors at the state and federal levels of government, and government is not always predisposed to accepting criticism from recipients of government services. Furthermore, as Dr. Hahn points out, the disabled minority is often fragmented making it difficult for government policy-makers to obtain representative views from the disabled minority. Again, as Dr. Hahn observes, many members of the disabled minority do not have the personal resources nor mobility to organize into groups with collective identities. Is it the function and responsiblity of government to provide resources for these purposes? Finally, who shall accept the challenge and share the responsibility for the development of a positive sense of identity among persons with disabilities? Isn't this the dominant reason why the rehabilitation profession exists, because it **values the rights, worth and dignity of persons** with disabilities?

In addition to the measures proposed by Dr. Hahn to mitigate the anticipated conflict between

proponents of traditional programs and disabled rights advocates, it is essential that public policymakers, professional leaders and spokespersons of the disabled minority collaborate on:

1) *A national policy on disability, incorporated in federal legislation, which avers the right of disabled people to have equal opportunity to participate fully in society with all of the responsibilities of citizenship.*
2) *Strenthening and/or clarifying federal anti-discrimination requirements such that a national policy on disability can be realized, and*
3) *Assuring that representatives of the disabled minority have significant and methodical input on proposed legislation, on the development of program priorities and policies, and on the allocation of resources for rehabilitation and other programs which have a substantial impact on disabled persons.*

Much of the structure to achieve these goals is already in place; what is missing is a long-term commitment among the leads of the various constituencies to sustain their efforts to change the behavior of society toward persons with disabilities. While the goals are ambitious and difficult, they may comprise the only game in town in which we can all play as equal partners.

-- TERRY CONOUR

It is tempting to embrace Dr. Hahn's paradigm of the "minority group" status for persons with disabilities, thus placing the burden of accommodation on society and public policy to provide an environment "designed to meet the needs of each of its member." However, following are questions which I have with this viewpoint:

1. Dr. Hahn's examples of "universal design" and "individuation" refer to people with physical disabilities. How does this model address the needs of mentally retarded and mentally ill persons?
2. How does the "minority group" model impact on governmental allocations for scientific and medical research to "prevent" or "cure" diseases or injuries which result in disability? I do not believe that current research reveals that disabled people are universally in agreement that it is "better" to be disabled than not, and I do not think we can ignore the existence of disabilities which are progressive in nature or painful to the individuals. Does the acceptance of Dr. Hahn's "minority model" really "meet the needs of each of its members."?

-- ANNA FAY

Dr. Hahn sets forth a closely argued position on why the handicapped should define their place in society instead of the able-bodied. He argues against the paradigm of the able-bodied, namely, that of "functional limitations." For the able-bodied, the disabled are clearly different, i.e., limited in ability to function. Surrounding this primordial judgment of "imperfection" associated with the humanity of the disabled are a variety of prejudicial **sequiturs** -- all of which isolate and otherwise relegate the disabled person to second-class status.

Based on this analysis, Dr. Hahn suggest the counter-paradigm of "minority group"status as better for the disabled persons themselves in identifying with that aspect of their humanity which the able-bodied stigmatize, so as to organize and mobilize politically around it. Thus, if the 36 million disabled persons in the U.S. were to put aside their categorical differences in type of physical or mental impairment that causes the able-bodied to discriminate against them, the disabled interest group would be powerful indeed. Dr. Hahn's analysis suggests that the major work of the disabled and the rehabilitationists should be political, i.e., organizing in order to exercise political influence.

I agree. As a rehabilitationist, I have witnessed the emergence of the disabled power bloc. Since passage of Section 503 and 504 of the Rehabilitation Act based on civil rights rather than "treatment" or "care" notions of what disabled persons need, there has been substantial progress in defining the nature of disability or handicap, the obligations of the rest of society toward disabled members, and the like.

Dr. Hahn's policy implication section is suggestive of some new directions. I am hopeful that these suggestions can be expanded and spelled out in terms that permit translation into concrete actions (e.g., legislative change, rehabilitation training curriculum changes, redesign of disability survey instruments, etc.). My sense is that until concrete changes are introduced into the basic institutional fabric of our society, the disabled will continue to be stereotyped as inferior human beings who deserve the "milk of human kindness," but no serious adjustment to limit socially imposed disadvantage.

If dramatic break-throughs are to come in the next 15 years, there must be daring conceptualization and action. Incrementalism will wear everybody down. Why not turn disability and the disabled into something that is valued in America? Why not make the disabled an **economic asset for employers** and able-bodied workers who are for-

tunate enough to work in the same firm with disabled workers?

To, this end, I would urge passage of tax legislation which would exclude from taxation all revenues which are produced by disabled workers. To be sure, there might be some quibbling over who is disabled. But so what? Now the quibbling is over the definition for purposes of paying an income transfer such as SSI or SSDI. Far better to quibble over how many bona fide disabled persons the firm is employing and how productive they are as producers of the firm's revenues!

-- JOHN H. NOBLE, JR.

While all who read Dr. Hahn's paper will undoubtedly agree with and applaud his championing of the minority model of disability, we would also undoubtedly agree that it is better to not have a disability than to have one, and that it is better to be in the majority than the minority. On these grounds, I propose that we not seek to abandon the "functional limitations" model, but rather seek to adapt it to the concepts underlying the minority model. I further propose that the real enemy is the care-giving model.

There is a certain inconvenience associated with loss of function. If a person loses the ability to walk, they must either find someone or something to help them be mobile or arrange their lives so they can function being immobile. Whatever capacity they may have to regain the ability to walk should be pursued within reason and within their priorities. If it is less restive and more productive to wheel than walk, then walking should not be stressed purely on its own merit. This is the fallacy of the functional limitations model -- it places function for its own sake over life quality productivity. The concepts of independent living can be used to replace this priority system with one based on values less tainted by paternalistic traditions.

It is not the provision of functional improvement services that is in conflict with the minority model, it is the manner in which services are provided. Dr. Hahn states that policies and programs which regard the delivery of services as the sole or principal means of aiding disabled persons are incomplete and self defeating. They are by definition incomplete because they address only one component of a very complex problem. They are self-defeating only if they see the provision of the service as an end instead of a means to a higher quality of life and actively try to create dependencies on their services. He further warns that independent living programs (ILP)are tending to join the ranks of the traditional service provider. I prefer to regard them as having more potential than others of becoming utopian service providers. Granted, there is a strong temptation for them to merely replace the "walking and working" norm with a "live in your own apartment and drive your own van" norm. I have hope, however, that the peer role model and the values of quality of life which lie at the foundation of the independent living movement will save ILPs from that fate.

Consistent with the minority model is the rejection of "care" and the demand for services. The hard won victories of the disability rights movement have established the minority model as valid for the disabled population. It must now expand its focus to advocate for the replacement of paternalistic care-givers with quality of life service providers. The combined approach of enlightened services for functional improvement and advocacy for universal access could effectively eliminate the need for a minority model altogether.

-- MARGARET A. NOSEK

This is an excellent text clearly defining and relating the **medical,** the **economic,** and the **socio-political** orientation regarding disabled persons and their environment.

I would like to see that environment include the Arts; so that the quality of life would benefit from the cultural enrichment now available. I have watched the beginning of this in a state Museum of Art recently visited by the National Rehabilitation Association. A description was recorded in an issue of the **Journal of Rehabilitation.** This is accompanied by an account of a Cultural Services Program replicable in the clinical phases of a hospital-based rehabilitation program.

Hahn mentions the "rich insights" which disabled persons might contribute to the remainder of society. One wheelchair patient personally organized a neurobiological research effort for regeneration of the central nervous system aimed at freeing paraplegics from their wheelchairs. The Wakeman Award is given to the best research in this effort every two years.

Hahn also states: "if prejudicial perceptions are ... a source of difficulties for the disabled ... there would seem to be a pressing need to reconceptualize the issue." I refer to my criticism in review of Chapter 3 in which the concept of old age is "enfeeblement," beginning at the age of 40 -- as in need of reconceptualization clinically and also socio-politically. Our approach to prevention of the diagnoses related to aging is still in the developing stage insofar as applying modern techniques in a rapidly growing population eligible to

utilize these techniques. It is mandatory ethically that these new concepts mentioned in the criticism of Chapter 3 be explored.
-- JAMES H. SEMANS

Dr. Hahn's paper was both illuminating and provocative. It stimulated a questioning and philosophical thought process which is sometimes dormant in those of us involved in the day to day practice of rehabilitation counseling.

Surprisingly, I was struck by the parallel between Dr. Hahn's analysis of the shifting-paradigms and the shift from Newtonian physics which was brought about by theories of special relativity and quantum mechanics. The intellectual exercise brought forth a number of points which warrant further examination both at the Switzer Seminar and in future forums. These points are developed below:

1) Theoretical frameworks versus philosophical orientation.

Is any one framework capable of adequately describing and operationalizing a subject as complex as disability? The socio-economic definition of disability would seem to suggest a tendency toward multiple frameworks: e.g., those addressing the individual, those addressing the interaction between the individual and the environment, and those addressing the individual, the environment and the interaction. Could it be that the apparent shift in paradigms beginning today is more like a pendulum swing with the more operational frameworks being between the two extremes of the functional limitations model and the minority group model?

Perhaps the philosophical orientation of the minority group model is what has been needed to stimulate approaches to rehabilitation which recognizes and respects the rights of persons with disabilities.

2) The Minority Group model appears to be a philosophical advance with potential political pitfalls.

a) The visionary concepts of the minority group model are necessary for training of rehabilitation counselors (RC). The RC must respect the rights of persons with disabilities and be fully cognizant of the laws and regulations which protect or impede these rights. He or she must also possess the ability to **envision** an environment in which the effect of disability is minimized or negated. The vision alone is not enough. The RC must possess the skill to analyze and define environmental impediments and then to formulate and implement plans to mitigate their effect.

b) Nonjudicious applications of the minority group model could potentially impede achievement of its goals.
   1. In a political era which has increasingly seen a backlash to the movements of the sixties, the disability movement could suffer some setbacks. The political climate evidenced by the last election could signal a danger to emerging minorities.
   2. On an individual level, an over emphasis on the environmental dimensions of the minority group model could decrease perceived personal responsibility and this effort to control those individual dimensions within the purview of individual rather than environmental control. In other words, a disabled adolescent might abandon his academic studies on the premise that society owes him a job whether or not he has secured the individual qualifications.

3. Separation of environmental and functional restraints.

Dr. Hahn suggests that the minority group model faces a crucial task in separating the restrictive effects of discriminatory stereotypes from environmental and functional restraints. One questions whether these can ever be separated. Stereotyping and prejudice can cause environmental and functional restraints and vice versa. With the two so intertwined, attempts to separate them would probably alter either component. Perhaps it is this concept which causes a heretofore diffuse discomfort with the **functional limitations model.** The functional limitations model, with its overt emphasis on individual measurement and definitions of limitations, may actually cause additional limitations. Are we very sure that the act of measuring a "functional limitation" does not actually enhance that limitation? In elementary physics, the Heisenberg Uncertaintity Principle tells us that the act of measuring can alter that which is measured.

Developing further upon this premise, one could see the potential awesome validity of Dr. Hahn's statement that "Disability thus exists primarily in the eye of the beholder." The frame of reference of the functional limitation model can predispose the perception of functional limitations. Measurement of limitations could theoretically alter their functional effect. For example, consider a hypothetical adolescent with a disability who is fully mainstreamed in school. To fulfill a regulatory requirement for a vocational assessment, the school

sends the student for a brief vocational assessment at the local rehabilitation facility. There the student finds himself in an environment where his fellow clients all have disabilities. The tasks used in the assessment may or may not be germane to his interests. Consider the potential implications on the student's self-image. Could not the act of measurement cause an alteration of self-concept? Although this may seem to be an extreme example, it points to the importance of rethinking the frames of reference with which we approach service delivery.

4) The Rehabilitation Counselor of Tomorrow.

The profession of rehabilitation counseling can play a key role in the positive emergence of the philosophy associated with the minority group model. To do so, the profession must embrace the "rights" philosophy and become true enablers. The rehabilitation counselor must be a visionary. He or she will be committed to a world where environmental and attitudinal changes abate or negate the effect of disability. The RC should be versed in law and regulations which protect or impede the rights of persons with disabilities. The RC must also possess a thorough understanding of the nature of disability from a physical, psychological, sociopolitical, and philosophical perspective. He or she must be fully cognizant of the potential limitations imposed by disability and the environment and be versed in methods of lessening potential limitations.

In essence the rehabilitation counselor should be able to assist the individual in optimizing his or her interaction with the environment. A crucial ingredient is the ability to envision what can be without being limited by what is. Perhaps, then, **creativity** should be one criteria for entrance into rehabilitation counselor training programs in the future.

In summary, Dr. Hahn's paper is an effective catalyst which can provoke an examimnation of philosophical orientations. Such examinations are needed if rehabilitation is to **prepare for the future.**

--EDNA M. SZYMANSKI

Dr. Hahn's extremely articulate presentation and argument for the adoption of a "minority group model" in program policy and operation was provocative and to many I am sure frightening. It is easy to accept its various assumptions, however I caution against too stringent an application of the idealist or utopian approach as being "the answer." The Black Movement in this country has certainly supported the need for and benefits derived from voluntary self identification as a minority group. The conscious decision to adopt as a positive "label", a previously perceived derogatory term, certainly instilled in many a sense of control over one's life and pride in one's heritage. I am, however, left with the impression that many consider the Black Movement to have succeeded in all of its goals; and to essentially be "over." Additionally, it appears to have evolved as a model, readily adaptable to all others who may experience the devastation and demeaning effects of discrimination. In the conceptualization, development and subsequent adoption of any model, attention must be given to the specifics that are indigenous to the population in question.

The choice offered in Dr. Hahn's paper seems to be one of acceptance of the "functional limitations model" versus the "minority group model." He argues elequently for the latter, at the seeming exclusion of the former. I submit that a recognition of the advantages of elements of both are necessary. Certainly, usuage of the "functional limitations model" with no attention or even, indeed, recognition of the individual as a person with a disability with certain "unalienable rights" is foolish, and dangerous. However, there are elements within the functional limitation model which can assist in realization of the latter ... (one hand washes the other). Too often, the imposition of a choice between one or another results is naught, or at best, benign acceptance of the majority ruling. Determining what is truly desired as an end result; looking realistically at those elements which impose (however, temporarily) reality constraints; developing objectives which are obtainable -- and which accomplish short-range results and concurrently **attack the removal of obstacles,** appears to me to be a more achievable method. I support "CAN DO IDEALISM." The "mood" of this country is not one at this point which will react favorably to "emotionalism," empathy or sympathy for the "downtrodden." Rather, it will react to a demonstration of unity which in turn will result in a recognition of economic clout.

It is interesting to note since much discussion is given to the definition of disability in all of the author's presentations, the definition contained in the **Webster's Seventh New Collegiate Dictionary** of **disability and disable.**

Disability is described as "the condition of being disabled ", and "non-legal disqualification, restriction or disadvantage."

Disable is described as "to deprive of legal right, qualification or capacity. To make incapable or ineffective, especially to deprive of physical, moral, or intellectual strength."

Certainly these definitions support Dr. Hahn's statement that the minority group model does not imply that these (aversive attitudes) can be chang-

ed by public education or rational persuasion. Strict enforcement of anti-discrimination laws as the principal policy will result in altered modes of behavior, which oftimes also results in modified attitudes.

One last comment relates to Dr. Hahn's statement when discussing the attitudes of employers, "nor may they be as capable of judging the qualifications of disabled job seekers as non-disabled competitors." I question the implied assumption that the average employer has a well developed capability in judging qualifications of prospective job-seekers generally. Publications such as the "Systems Approach to Task Analysis and Job Restructuring" published by the W.E. Upjohn Institute on Employment Research, cites the overwhelming disparity between employers' abilities to distinguish between "what gets done" and "what workers do;" or any real understanding of the involvement of three areas in each task: that of "things, data and people." It falls upon the shoulders of the vocational rehabilitation agency to ensure that counselors and specialists involved in the direct placement of individuals with disabilities, not only are familiar with the specific aspects which impact on an individual's performance of tasks, but also understand the options available for analyzing those tasks and redesigning them in a fashion, (if necessary) which "gets the work done."

-- JANICE A. WOODWARD

Summary of Recommendations

The following is a summary of the recommendations and implications for action developed by the Switzer Scholars as they relate to the topic of Chapter Four. (The Recorder was Jane E. Myers)

1. Recommendations/implications that would enhance service delivery:

That the goal of all disability related services be **independence and quality of life.** The implications of this goal for service delivery, program development, policy, training, research, and legislation should be fully explored.

That a concerted effort be made to utilize the existing national, state, and local structures of task forces, committees, and similar groups to encourage and foster cooperative linkages between disabled consumers, rehabilitation professionals, business and industry.

2. Recommendations/implications for policy or program development:

All disability related "policy boards" should include a substantial number of **qualified** disabled people.

3. Recommendations/implications for training of staff, the general public, etc.

Training curricula in all disability-related programs should be reassessed and revised to meet the current and future needs of disabled persons, rehabilitation professionals, and business/industry.

4. Recommendations/implications for needed research:

Research should be conducted on the **meaning of independence** and methods of measuring it.

Research should be conducted to **redefine evaluation criteria** to have a non-numeric focus that reflects the goals of rehabilitation services as independence and quality of life.

5. Recommendations/implications for legislation -- Federal, State, Local:

Entitlement to financial and service support should be available to offset the extraordinary independent living costs experienced by disabled individuals.

Enforcement of **affirmative action legislation** affecting disabled persons should be a priority consideration.

6. Recommendations/implications for any areas not categorized in the above listing:

Universal access, in the broadest sense, should be the standard for all new endeavors, i.e., new buildings, shopping malls, schools, houses of worship, etc.

Disabling language should be eliminated from all disability-related communication.

A concerted effort should be made to recruit and train disabled individuals for work in disability-related professions and this includes Rehabilitation Counseling.

Disabled persons should be recognized as a minority subject to invidous discrimination under the equal protection clause of the 14th Amendment (due process and equal protection) and judicial bodies should acquire this understanding of disability.

Switzer Scholar Noble

Chapter Five

Ethical Considerations Facing Society in Rehabilitating Severely Disabled Persons

By John H. Noble

This paper is about life's beginning, life's ending and life's preservation in face of judgments about the degree of perfection or imperfection of individual lives. It is about wanted life and unwanted life. Above all, it is about how society will permit its members to act on these judgments about the perfection or imperfection of these lives. The changing times are causing renewed debate about these matters. In my view, the consensus that emerges from the debate will have a profound influence on the lives -- indeed, the chances for life -- of severely disabled persons. That consensus will inevitably be translated into resource allocation decisions by society's institutions and will define the purposes and practice of rehabilitation. At issue is how far and at what cost society will go to protect and nurture its disabled members. For this reason, disabled people and rehabilitation professionals have a large stake in the outcome of the debate, and must become immediately involved.

The Emerging Debate

The newspapers are filled these days with stories about scientific discoveries with great potential for saving or extending life, or about the actual application of some new technology to save a life that would have been lost without it. On the same day, we read of the isolation of a gene that plays a crucial role in the body's immune system, making possible manipulation of that system to fight disease or prevent organ rejection, and the progress of Baby Fae, who is making history as the longest survivor of an animal heart transplant (Richomond Times Dispatch, November 1, 1984). We think to ourselves or exclaim, "How marvelous! Let's hope and pray for Baby Fae's survival and for the wonders of science to continue."

The newspapers also report not so happy news. One story is about William Bartling who suffers from five usually fatal diseases and wants his breathing machine turned off so that he can slip into death naturally. But a State court denies Mr. Bartling's plea on the grounds that turning off the respirator would at best be aiding a suicide and, at worst, be a homicide. Meanwhile, Mr. Bartling, whose medical, hospital, and legal bills have reached $500,000, must appeal the court's decision and hope for its reversal (Richmond Times-Dispatch, October 21, 1984).

Another story is about Ronald Goldberg, who, after eight heart attacks and two strokes, has been scheduled for a heart transplant at a VA hospital in Richmond, Virginia (Richmond Times-Dispatch, August 27, 1984). Instead of being ecstatic, he is asking some troublesome questions:

Why isn't everybody given this chance? I am getting a second chance becuase I happened to put on a uniform for my country. I've talked to my fellow transplant patients. They all ask the same question. Why can't our country offer this to everybody?

Still, another story tells how a task force of federal government agency heads ducked "the politically tricky question" of what the government's approach should be toward helping families who struggle with the catastrophic consequences of Alzheimer's disease; how the task force's final draft report deleted recommendations for financing the

extended health care needed by victims of Alzheimer's disease (Richmond Times-Dispatch, September 25, 1984).

Finally, the recent election for the presidency provoked ugly confrontations on the abortion issue. One of the presidential candidates, several religious leaders, and national pro- and anti-abortion groups pressed their views with inflammatory rhetoric. There were attacks on abortion clinics and bombing at night. William Baird, an abortion activist, depicted the violence against abortion clinics as causing the clinics and doctors to arm themselves and laying the "groundwork for a religious war" (Richmond Times-Dispatch, October 1, 1984).

All of these newspaper accounts except the last one are about people with disabilities. The abortion debate, of course, addresses the issues of when legally protected life begins and whether and under what circumstances a pregnant woman has the right to resort to abortion in order to prevent the birth of an unwanted child.

The relevance of the abortion issue to the question of how far society will go to protect and nurture disabled people becomes apparent by consideration of two cases. First, very low weight (500-750 grams) infants of parents who want them often receive expensive neonatal intensive care to enable them to survive -- often with a disability as the result of prematurity. In stark contrast, unwanted normal fetuses weighing as much as these wanted premature infants are aborted at the legal limit of 28 weeks in the United Kingdom and 26 weeks in the United States (Young, 1984). Second, laboratory examination of therapeutic abortions to avoid the congenital rubella syndrome following a rubella outbreak yields one false-positive case in twelve abortions and six possible but not definitely confirmed cases (Serdula, et al., 1984). From these two examples, one can see how much latitude Western society permits in avoiding unwanted or defective children.

Beyond coverage by the news media of the mixed benefits and costs of the emerging medical technology, medical, religious, and political leaders, as well as a variety of non-medical disciplines, have begun to express concern about how society and its institutions should cope. Legislators and the courts are struggling to balance the competing claims and interests of hospitals, physicians, families, and individual patients. Medical committees seek new definitions of death and of the doctor's obligations to his patient. Some physicians and ethicists advocate adoption of a "quality of life" formula in deciding which low birthweight infants to save -- one that takes into account not only the individual's physical and intellectual capacities but also the potential contributions to the individual of the home, family, and society (Young, 1984).

The bioethics literature is rapidly expanding (Spicker and Engelhardt, 1977; Steinbock, 1980; Shelp, 1981). Economics have begun to apply cost-benefit analysis to the decision-making process and have identified the birthweight below which intensive care yields a net economic loss in terms of the "quality-adjusted-life-years gained" (Boyle, et al., 1983). Professional associations and their policy spokesmen are beginning to focus on bioethical issues and their implications for practice, urging that practitioners give proper concern to due process in life-or-death questions and, when necessary, play the role of the whistleblower in instances of abuse, neglect, or exploitation of children or adults (NASW News, September, 1984).

Inequality, Scarcity, and the Rationing Of Life and Opportunity

What is one to make of all of this? Is there a frame of reference that permits clarification of the choices which society and its institutions must make to protect the rights of individuals and families in times of crisis?

In my view, the scarcity of a society's resources and the inequalities that are permitted to exist among classes of people explain how life and opportunities are rationed. Indeed, the society's sense of affluence or deprivation and the extent of belief in its ability to satisfy competing demands for the use of limited resources appear to shape the response to newly emerging needs. This reality is captured by the gut reaction of a rehabilitation worker from Pakistan visiting a neonatal intensive care unit in Washington, D.C., under the supervision of a foreign doctor from the Cameroon:

I was, frankly, horrified to see the tiny mites festooned with tubing, cut off from humanity, in the grip of the machines. We learned that about half the survivors would be damaged for life. And the cost per premmie? $88,000. I thought of my budget. ... The doctor in charge of the premmie unit was one resource that had been drained from his native country to spend $88,000 per premmie in the USA. He could not now go back ... there was nowhere in his own country for him to use his advanced skills. Most Cameroonian mothers do not have even a sterile blade with which to cut the umbilical cord. ... I'm not an egalitarian. There are rich countries in the world and there are poor countries: there are fat men and thin men; that's the way it is. But sometimes the irony bites at the soul. (Miles, 1984).

The cultural and economic relativity of a society's response to human need is further illustrated by the treatment of severe mental retardation in India, Denmark, and the United States. In India, the problem is not even readily apparent amidst the prevailing conditions of poverty and human misery. Infant and childhood mortality rates are appallingly high. The odds against survival mean that few severely mentally retarded children in India will survive, with or without assistance. Children born with normal intelligence will grow up manifesting the insults of malnutrition, poor health care, and limited educational opportunites. In India, the effects of deprivations are everywhere, and mimic the symptoms of mental retardation in other countries.

Denmark stands at the other extreme. A recent Danish study (Pruzen and Spohr, 1982) describes a society in which the central objective is "to normalize the handicap's conditions." Extensive assistance is offered to mentally disabled individuals and their families. Seventy-nine percent of the families with mentally disabled children receive payments for "necessary additional expenses;" 87 percent of the mentally disabled individuals, 18 years or older, had a disability pension; and 33 percent with a disability pension receive an additional allowance for a personal attendant or other form of personal assistance.

Looked at from the Indian perspective, the Untied States is incredibly advanced in what it can do for its mentally retarded citizens. From the Danish perspective, on the other hand, the United States is extremely backward in its practice of normalization and, in general, not very generous toward disabled people and their families, despite the great strides that have been make in the past 10 years in securing their rights and meeting their needs. While federal and state budgets have expanded to fund the entitlements and programs created by the Developmental Disabilities Assistance and Bill of Rights Act, Section 503 and 504 of the Rehabilitation Act, and P.L. 94-142, the Education for All Handicapped Children Act, the expectations created by these landmark pieces of legislation still exceed the budgetary response.

It is becoming commonplace for scholars and policy analysts (Aaron and Swartz, 1984; Fuchs, 1984; Simmons and Marine, 1984) to express concern about the changing demography of the United States and to question how the nation will pay its growing medical care and pension bills. According to Fuchs (1984), the needs of the elderly are more related to the proximity of death than to age by itself. While per capita expenditures on health care do increase with age, they are highest in the last year of one's life. Thus, Fuchs urges achievement of social consensus about appropriate care for the dying and more flexible labor market arrangements to promote continued work activity (and less reliance on pensions) among older men and women. According to the Population Reference Bureau (1984), if cancer and heart disease are eliminated, millions of lives will be prolonged and will cost the Federal government billions of extra dollars. It recommends that the escalating costs to society of increased longevity be assessed and planned for, since programs for the elderly cost more than the taxes paid by them.

How does a modern society with a struggling economy go about rationing health care? Aaron and Swartz (1984) describe how the British health care system lives within the fixed budget set by the national government. They depict a "top down" budgeting process, which transfers funds successively from the national Treasury to regions, districts, and individual hospitals. The budget reflects the prior year's outlays and anticipated inflation. If prices rise faster than anticipated, or the region, district, or hospital overspends its budget, then the amount of excess spending is subtracted from the next year's budget and ways must be found to cut back. Certain life saving procedures, such as renal dialysis, bone marrow transplantation, and total parenteral nutrition, are severely restricted. Other treatments, such as chemotherapy for cancers of the colon, pancreas, and stomach, are not often provided. In this way, the depressed British economy is able to pay its medical care bills.

How do macro-budget decisions get translated into decisions involving individual patients? According to Aaron and Swartz, beliefs, attitudes, and practice make it possible for the British to curtail the availability of certain kinds of treatment. Many British oncologists, for example, doubt the efficacy of treating most metastatic solid tumors--"there is little hard evidence to show that the duration of life of a good quality is usefully extended" (p. 49). In contrast to the United States, British patients have less knowledge of the latest medical advances and are less aggressive in pressing for treatment. There are less than one-tenth the number of oncologists per capita in England and Wales than in the United States. The salaried status of British oncologists removes the incentive to treat hopeless cases. Under the fee-for-service system in the United States, one British oncologist noted, "it is increasingly hard (for patients) to escape chemotherapy" (p. 49). With respect to renal dialysis, resource constraints that vary from region to region determine how many patients are accepted for treatment. Unlike in the

United States, few otherwise healthy sixty year old patients are treated for renal failure. What is more, those who are not selected for treatment and their relatives are probably aware of the fact.

Simmons and Marine (1984) concur with Aaron and Swartz's conclusion that the British fixed budget system accounts for lower rates of treatment with high-cost technology than in the United States where the fee-for-service marketplace prevails. They see the United States fast approaching a financial crisis that will force it to make priority decisions about the use of costly medical technologies, and note that the high expectations of Americans will make the issues of cost control and the rationing of medical care difficult to resolve.

The need to ration medical care in the United Kingdom, as well as to limit other social costs, is reflected in the treatment of very low birthweight infants. Unlike in the United States, infants weighing less than 750 grams seldom receive aggressive treatment (Young, 1984). This is also true in Sweden with its much higher standard of living and ability to pay the initial hospital bill and the on-going costs of disability. Disability taking the form of mental retardation, hearing loss, or spastic disorders occurs in about one-in-four survivors weighing less than 1,000 grams at birth.

According to Campbell (1982), a professor at the University of Aberdeen in Scotland, the cut-off weight for intensive neonatal care should remain "flexible and dependent on such factors as gestational age, the state of the infant at birth, the presence and timing of complications, the parents' view and the family circumstances, and the available resources." It is arguable whether Professor Campbell's decision criteria would satisfy the U.S. government's recently published regulations in response to the Baby Doe case. Clearly, culture, economic circumstances, and political climate account for the differences in U.S., British, and even Swedish intensive neonatal care practices.

Disabled people are often denied access to less controversial services than medical care because of their limited supply and/or policies that seek their most cost-effective deployment. Theory and practice tend to reinforce one another in this regard. Health capital theory (Grossman, 1972a, 1972b; Berkowitz, Fenn, and Lambrinos, 1983) and labor queue theory Levitan and Taggart, 1979) reach essentially the same conclusion: In good times and bad, employers prefer to hire the ostensibly healthier and more productive workers. In times of economic recession, disabled people are most affected. Indeed, the overall benefit-cost ratio of rehabilitative services is reduced, since disabled people face stiffer competition from the able-bodied for few available jobs and often fail to obtain a job after receiving expensive services.

Numerous cost-benefit analyses of the Federal-State vocational rehabilitation program in the United States have been conducted in the effort to win support for increased expenditures, as well as to discover which classes of disabled persons might show a greater rate of return for the investment in them (Noble,1977). Overly simplistic forecasting of the future earnings of rehabilitants, the insufficiencies of data concerning the benefits and costs of rehabilitation, and the extreme sensitivity of the results of cost-benefit model to its untested underlying assumptions have prevented priorities from being set on the basis of class-specific calculations. Rehabilitation agencies have not been daunted by these limitations, however.

When State rehabilitation agencies have had to take budget cuts, they have used intuition and fragmentary clinical data to decide where to deny or limit services. For example, under the Omnibus Budget Reconciliation Act of 1981 the terms for reimbursement of services to Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) beneficiaries changed drastically and caused a substantial drop in the total investment in this population (Noble, 1984). Generally but not without exception, the hardest hit classes of disabled people were those with mental illness, mental retardation, and character/personality disorders. The selective rationing of services occurred despite evidence that 45 to 70 percent from each disability class were rehabilitated into jobs paying more than 150 percent of the substantial gainful activity (SGA) wage of $300 per month and that, therefore, nobody simply on the basis of the type of major disabling condition should be denied access to vocational rehabilitation.

Ironically, the attempts of government to limit direct program costs sometimes have the perverse effect of increasing both the direct and indirect cost burden of disability on society. For example, prior to the passage in 1980 of Sections 1619 (a) and (b) of the Social Security Act, disabled recipients of Supplemental Security Income (SSI) had little or no incentive to take a job paying more than the substantial gainful activity (SGA) wage of $300 per month because they could easily end up with less income than they would with a job paying less than the SGA wage (Noble, 1984). In this instance, the eligibility rules designed to curtail transfer payments by removing disabled people from the SSI rolls as quickly as possible had the contrary effect.

In the same vein, Gellman (1983) documents how the British Employment Service in face of budget cuts revised its approach to serving handicapped persons by integrating the disabled into its general placement program for able-bodied job seekers, offering less intensive services, and requiring disabled people to assume greater responsibility for locating and securing employment. No effort was made to increase the funding or priority given to modifying the job site or equipment. This has reduced the intensity of individualized services and detracted from job location and placement efforts, which most vocational counselors believe are the key to the successful rehabilitation of disabled people. In this instance, spreading rehabilitative services too thin seemed likely to frustrate the intent of spending the money in the first place.

Summarizing,all evidence points to the reality of rationing and selectivity in face of the scarcity of resources. Rationing decisions are made at the beginning, the end, and throughout the course of individual lives. At the root of the rationing decisions are judgments about the degree of perfection or imperfection of these lives. The threshold for selection or rejection appears to vary with the society's culture and economic circumstances, as well as the decision-maker's contextual sense of the benefits and costs that will accrue for the individual, family, and the community. The quest for a "quality of life" formula or a set of principles to ease the burden of choice is understandable, given the soul-wrenching nature of some of the decisions that must be made.

Applicable Ethical Principles

Is there a set of principles, or better yet, a single principle or formula on which individuals, families, the professions, government, and the community at large can rely as a guide in these difficult matters? Could the Hypocratic maxim **primum non nocere,** "above all, do no harm," be generalized to cover all contingencies? As things stand, more and more medical practice is being scrutinized and questioned. Practioners complain about the intrusiveness of government and the courts and its disruptive effects (Wirth, 1984).

Contemporary writings on bioethics do not offer any "quick fix" or formula solutions to the ethical dilemmas that rapid advancements in science and medical technology are creating for everybody involved. However, the do-no-harm principle, while not offering clear-cut answers in every case, does promote sensitivity to the interests of all parties in the search for ethical solutions in "life or death" decisions. Jonsen (1977) identifies four ideal types or "uses" of the maxim: (1) medicine as moral enterprise; (2) due care; (3) risk-benefit ration; and (4) benefit-detriment equation. In my view, these usages of the do-no-harm principle should be the takeoff point not only in deliberations about what to do in individual cases but also in setting public policy.

Medicine (or any other professional practice) is a moral enterprise which applies knowledge and skills to benefit human beings. The do-no-harm principle warns practitioners against their abuse. The writings through the centuries about the role of the physician tend to the view that physicians are not morally free to apply their skills as they see fit; they must use them only to benefit persons in need.

"Due care" in medicine requires practitioners to continuously improve their knowledge and skills and to reappraise them against the standards of changing knowledge and practice. In this usage, the do-no-harm principle translates into legal liability insofar as malpractice claims typically assert failure to exercise due care under the accepted standards of knowledge and practice. At root, it enjoins the physician to be prudent, taking care to properly diagnose and treat conditions according to the prevailing standards.

Given the uncertainty of outcome for many medical procedures, the do-no-harm principle requires the physician to assess accurately as possible the benefits and risk of specific forms of treatment. What is more, the physician should share his knowledge of the statistical and clinical risks with the patient so that the patient's decision to accept treatment is fully informed. The patient's knowledge of the benefits and risks of treatment is very important, since different individuals have differing risk-taking tendencies. At stake here is the patient's right to make a personal choice about the degree to which his personal integrity and security may be invaded. According to Jonsen, "harm" is done to a patient who does not understand and, therefore, cannot consent to the medical procedure and its consequences. When the patient is incapable of giving consent, a surrogate (at times to physician) must attempt to assess the benefits and risks in place of the patient, taking into account both their extent and how the patient would likely respond if he were capable of evaluating them.

Last, the do-no-harm principle requires that the physician consider and share with the patient the degree of detriment or harm that may necessarily accompany the benefits of treatment. In this usage, the patient must again have the benefit of the physician's accurate assessment. In the final analysis, on-

ly the patient can judge whether the benefits of the treatment outweigh the accompanying detriment or costs. On calculation of these benefits and costs, some patients decide not to undergo treatment because the costs are personally unacceptable; e.g., the transplantation of an organ with the accompanying pain and uncertainty about possible rejection.

When applied to single cases involving actions taken by the physician, the do-no-harm principle provides relatively straight-forward guidelines often buttressed by the law. Thus, the physician is never allowed to kill a dying patient to end his suffering. But what about the omission of an act when, for example, the physician decides not to put a comatose dying patient on a respirator (Case #1)? And what if the physician takes the dying patient off the respirator after he has been placed on it (Case #2)? In these cases, the do-no-harm principle is applicable but less clear.

Fletcher (1980) argues that the physician in both cases "permitted" death to occur rather than "caused the patient's death. Legally, no criminal liability exists for a physician who takes no action in a given situation and death ensues, provided that the physician's omission is consistent with the prevailing medical standard of practice. The omission in case #1 is clearly justified if consistent with the prevailing medical standard. In case #2, however, the reasoning is tortuous. If the special relationship between the physician and patient includes the expectation that the physician will act as surrogate for the patient in deciding to discontinue treatment at the point which the detriment accompanying the benefits of treatment becomes unacceptably high, then the physician is justified in taking the dying patient off the respirator. Thus restored to his prior "untreated" state, the patient dies naturally. In this way, death comes about as the result of an omitted rather than a committed act. Except for the choice of the surrogate, this was essentially the reasoning of the Supreme Court of New Jersey in the case of Karen Quinlan (70 J.J. 10, March 31, 1976) in its decision to allow Ms. Quinlan's physician to remove her from the respirator. The unacceptably high detriment was Ms. Quinlan's loss of privacy, i.e., the massive invasion of her bodily function without hope of restored cognitive life.

The do-no-harm principle is applied with considerable difficulty to situations where medical procedures distribute benefits and detriments to different parties. Within this realm of bioethical issues are abortion, non-therapeutic experimentation on subjects incapable of consent, the allocation of scarce biomedical resources, and sterilization of dysgenic persons. Calculating the morality of multiple effects ultimately requires appeal to some "higher" value beyond simply the greater good of another or the greater good of a greater number of others to justify the harm that is done to one or more others. According to Jonsen (1977), the appplication of the do-no-harm principle to these problems requires "serious or proportionate reasons for allowing a detriment which is necessarily concomitant with a benefit" (p.38). The freedom of another over her own body is often cited as the serious or proportionate reason that justifies permitting the fetal death in a medically induced abortion. This line of reasoning has been advanced to justify non-intervention, if not active measures, in cases where the quality of the life saved would be so painful, poverty-stricken, deprived, and oppressive that it would distort all possible meaning which the person living that life could attach to it.

Reform Proposals and Unresolved Issues

In view of the ethical complexities involved, how should society go about protecting the interests of vulnerable disabled persons whose devalued lives are easily sacrificed by nondisabled people for a variety of reasons, including the cost burden they impose on the family and the rest of society? The Baby Doe controversy focused attention on the bioethics of disabled infant care in hospitals. What goes on in hospices may become the next focus of attention. Serious concerns have been expressed about the dangers of hospice care for people with mental retardation (Gibson, 1984; Wolfensberger, 1984). There is fear that hospices will become society's instrument for terminating "lives not worth saving" because they lack sufficient quality or cost too much to maintain. In his reflections on the hospice movement, for example, Wolfensberger (1984) reacts against the ethicist Willard Gaylin's proposal that hospices for the dying might be used by people like Elizabeth Bouvia, the young cerebral palsied woman who decided to kill herself but could not obtain the assistance of a traditional hospital.

A major beneficial effect of the Baby Doe controversy has been passage of the Child Abuse Amendments of 1984 (P.L. 98-457), which define an enforceable standard of medical care for infants with life-threatening conditions under federal and eventually all state laws. This standard applies to all infants, whether or not they suffer single or multiple disabilities. Besides setting the medical care standard, the Amendments require, as a condition for receipt of federal funds for child abuse programs, that the states establish procedures or programs within the state child protection system to coordinate and consult with designated individuals

within all health care facilities in cases of suspected medical neglect. In addition, the states are required to provide authority under state law for the child protection system to pursue legal remedies to prevent the withholding of medically indicated treatment.

The standard of medical care adopted by the U.S. Congress is defined in the negative sense of what is meant by the term, "withholding of medically indicated treatment," namely:

... the failure to repond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's or physicians' reasonable judgment. (A) the infant is chronically and irreversibly comatose; (b) the provision of such treatment would (1) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening condidtions, or (iii) otherwise be futile in terms of the survival of the infant; or (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane (P.L. 98-457, Section 121).

This definition clarified the do-no-harm principle of medical ethics in its usuage as a benefit-detriment equation. In my view, it could well serve as the legally enforceable standard of medical care for people of all ages throughout the country. Its adoption as a national standard might obviate the need for creating the questionably legal "living will" as the way to avoid use of extraordinary means such as the respirator to needlessly prolong dying.

P.L. 98-457 requires all health care facilities to designate an individual to coordinate with the state child protective system in cases of suspected medical neglect. This provision does not address how health care facilities should go about monitoring the practice of physicians within their confines, nor how physicians themselves should monitor their collective practice within health care facilities. In my view, this unresolved question is critical to successful implementation of the new law. Again, in my view, it is far better for professionals to regulate their own practice than to submit to the heavy hand of government bureaucracy. The frictional costs of implementing P.L. 98-457 is thus within the control of the medical profession and the health care facilities in which physicians practice.

In reacting against the initial Baby Doe regulations, Wirth (1984) asserted:

. . . No two patients with handicapping conditions are alike. Each has its unique medical as well as social, religious, and human values. Neither the government nor the courts can quantify these values in my opinion. There is no way that our govenment or our courts can legislate morality in this very difficult decision (p. 22).

Instead of the Baby Doe Regulations, Dr. Wirth proposed creating a "moral community" for each case in which the right medical decision is unclear -- a community made up of the people who have to make the moral judgment about the value of the individual's life. This moral community would typically be established by the patient's family and be composed of people they trust, such as loved relatives, religious counselors, and physicians or other members of the medical community. Within the moral community, the varying opinions about what is right under the circumstances would be negotiated and consensus reached about the most appropriate care.

In my view, Dr. Wirth's proposal has great merit. It appears consistent with the intent of P.L. 98-457 and the latitude for judgment that the Act offers within the definition, "withholding of medically indicated treatment." Under the usage of the do-no-harm principle as a benefit-detriment equation, the physician already has a duty to communicate to the patient or his surrogate the degree of detriment or harm that may necessarily accompany the benefits of treatment. What better way of adhering to the do-no-harm principle than for the physician to sensitively communicate the relevant information to the "moral community" and to participate in that community's decision-making process? As an addition to Dr. Wirth's proposal, I would suggest that the moral community, wherever possible, reach out to include as one of its members a persons with a severe disability which can share what degree of life quality is possible for a severely disabled person in American society. Nobody but a similarly situated person is capable of communicating the value that a life with a severe disability can possess.

Finally, we must turn to the matter of justice. Bioethical issues do not originate in a vacuum. Buchanan (1981) reminds us, "Since not only particular actions but also policies and institutions may be just or unjust, serious theorizing about justice forces us to expand the narrow focus of the micro approach by raising fundamental queries about the background social, economic, and political institu-

tions from which micro problems emerge (p.3). In the United States, the prevailing moral theory is that of utilitarianism. The good is defined independently of the right as happiness, satisfaction, pleasure, the realization of preferences, et. The right, in turn, is defined as what maximizes the good at either the individual or institutional level of society. Utilitarianism does not necessarily seek fairness -- only the maximization of aggregate utility. The utilitarian society is easily disposed to sacrifice the interest of the severely disabled individual for the aggregate good.

Other concepts of justice exist as alternatives to utilitarianism. One alternative is John Rawls' theory of justice as "fairness." In Rawls' just society, each person is accorded equal right to the greatest array of equal basic liberties; each person is afforded equality of fair opportunities; and social and economics institutions are arranged to yield the maximum benefit to the worst off. Somewhat related to Rawls' theory of justice is a variant (Burt, 1984) which appeals to the communal relationship or shared humanity of "normal" and disabled members of society. This communal relationship imposes a continuing obligation on "normal" individuals to listen and respond to the claims of disabled people who seek to actualize their human potential. In this view of justice, paradoxically, "disabled people cannot vindicate their claims without others' assistance" (p. 492). disabled people, like everybody else in society are constrained by "an inescapable economic and social network of interrelated dependencies" (p.493) and thus need the financial and emotional resources of others to achieve a measure of independence.

Another alternative, libertarianism, emphasizes the property right that individuals have to their persons and whatever they come to possess through either initial acquistion or transfer. The libertarian just society is stongly anti-redistributive and views coercive taxation for welfare programs as theft! However, charity in the libertarian society requires help from those who have no right to our giving, among them society's severely disabled members.

Both utilitarianism and libertarianism deny any basic right to health or any other form of care. However, utilitarianism permits assertion of a derivative right to health care if it can be empirically shown that such a right will contribute to society's maximum aggregate utility. Rawls' theory is silent about any basic right to health care, although Buchanan (1981) sees how Rawls' Principle of Equality of Fair Opportunity could be construed to require health care as a basic right in order to overcome the deficits in abilities and skills that hinder persons in the just society from enjoying equal opportunity to obtain social positions and offices.

Of the three concepts of justice, John Rawls' fair society or any variant which obligates "normal" individuals to assist disabled people clearly have the greatest potential to serve the self-actualizing interests of severely disabled persons. The fair society would try to maximize benefits to those who are worst off, compensating where possible for initial and acquired inequalities in health status and ability to perform life's functions. Utilitarianism or libertarianism will also suffice if it can be shown either that society's aggregate utility is maximized by serving the interests of severely disabled persons or that enough charity will flow to people who have no right to help.

Disabled persons and rehabilitation professionals have before them the considerable challenge of shaping which concept of justice will prevail in formulating general public policy choices and the individual decisions which follow. Our work is clearly cut out for us!

□

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Excerpts of Reviews and Comments

The following are excerpts of reviews, comments, questions and recommendations made by the Switzer Scholars. These are presented to further stimulate thinking, discussion and action as it relates to the content of Chapter Five by John H. Noble, Jr.

In this discussion of a frame of reference, weighing economic factors which permits society to protect the rights of individuals, I have the following concern with regard to future policy:

- Dr. Noble makes the assumption that there is a scarcity of resources in all societies. While this may be true in India, is it really the case in the U.S.A., or is the problem one of priorities and allocation of resources?

While I endorse the "do-no-harm principle" as a sound solution to the ethical dilemma of "life or death" decisions, my question is as follows:

- How does this take into account the practioner, however possessing of knowledge and skills, from possibly bringing with him/her to set of prejudgement and negative societal misconceptions to his/her assessment of the benefits or non-benefits of treatment? How might this affect the information he/she shared with the respective patient?

-- ANNA FAY

Most medical situations are approached ethically, first with professional information, formulated so that the meaning of the words used are familiar to the patient. Following this the patient should have an interpretaton of this information by another person amicable to the patient, preferably one who has lived with that ethical decision, e.g., a rehabilitated person with paraplegia.

Confidentiality should protect the patient from undue and irresponsible comments by others who are speaking of his situation without proper information.

The chemotherapy of cancer today poses an ethical problem between the physician and the patient. The patient deserves a candid discussion which should be as optimistic as the recorded medical results justify; but one which does not omit the discomfort and costs. Alternatives such as a hospice should not be omitted. A surrogate for the patient is justified, if his mental status indicates this.

Another principle mentioned by Dr. Noble is that no two patients are alike. Therefore, individualizing the medical decisions and the circumstances leading up to them is important.

Confidentiality without limiting the investigation of all possible routes of therapy and rehabilitation accompanied by a second opinion when indicated would seem to lead to the wisest possible decision, perhaps including the predictable disadvantages which would therefore become less undesirable because they were predicted and even sometimes softened by that preparedness.

-- JAMES H. SEMANS

John Noble raises some profound and troubling issues in his discussion of the "Ethical Considerations Facing Society in Rehabilitating Severely Disabled Persons." Life-and-death issues of whether to withhold or provide treatment, to disconnect vital life--support equipment, or to allow or abort the birth of a disabled fetus would seem to be of interest to only the intellectually curious among rehabilitation administrators and practitioners who rarely if ever become involved in such decisions. Yet, in each example Dr. Noble illustrates

how society through its agents (doctors, lawyers and courts) rations life and opportunity as it attempts to statisfy competing demands for the use of limited resources. Rehabilitation administrators and practitioners attempt to cope with this dilemma, albeit in less dramatic circumstances, on an almost daily basis and in a variety of ways.

A lack of resources with which to satisfy the demand for services is a common problem among state rehabilitation agencies. In former years it was not unusual for an agency to continue to spend case service monies until the funds simply ran out, at which time the agency would suspend intakes and service delivery until the next funding cycle began. More recently agency administrators have foreseen resource depletions and have instituted interim policies which have the net effect of slowing the rate of agency case service expenditures to the point that funds are available on a limited basis throughout a funding cycle. Such interim policies may include entirely eliminating certain types of expenditures, lowering the ceiling of the total expenditures allowed on a single case, or making more restrictive the circumstances in which certain high cost services such as psychotherapy or university training can be provided. None of these stop-gap measures is necessarily fair to disabled persons who have a legitimate need for a restricted or eliminated service.

Federal rehabilitation legislation requires that a state rehabilitation agency either serve all eligible handicapped individuals who apply for services, or operate under an "Order of Selection" which specifies how and who the agency will select to serve, when resources are insufficient to serve everyone. Since the legislation further requires that severely handicapped persons be served first under the "Order of Selection," the mandate is not unlike John Rawls' theory of justice as "fairness," in that resources would be expended as a matter of priority on those who have the greater need for services. Few state rehabilitation agencies have ever implemented an "Order of Selection" and those that have done so have reported administrative difficulties in implementing it throughout a statewide system on an equitable basis. So the problem remains; how can limited resources be distributed fairly and equitably over a population so that those most in need are served first? The **concepts of justice** offered by Dr. Noble deserve greater study of application in rehabilitation agencies.

– **TERRY CONOUR**

SUMMARY OF RECOMMENDATIONS
for Chapter Five begin on page 100

Special Papers

The Competitive Marketplace: A Partnership with the Rehabilitation Community Is Needed Now More Than Ever -- By Arthur Colby, Director of Human Resources, United Technologies, Hartford, Conn. (Page 82)

Economics, Rehabilitation and the Post-Industrial Society -- By Raymond A. Ehrle, Executive-in-Residence, Director of Research Support, Office of Research and Continuing Professional Education, The George Washington University, Washington, D.C. (Page 83)

New Horizons for Developmentally Disabled Americans -- By Jean K. Elder, Commissioner, Adminstration on Developmental Disabilities, U.S. Department of Health and Human Services, Washington, D.C. (Page 87)

Some Thoughts on Independence -- By Margaret A. Nosek, Coordinator, Independent Living Center, Baylor Medical School, Houston, Texas (Page 90)

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The Emerging Role of Disabled Hispanics -- By Antonio Suazo, Regional Representative, President's Committee on Employment of the Handicapped, Washington, D.C. (Page 94)

The Competitive Marketplace: A Partnership With The Rehabilitation Community Is Needed Now More Than Ever

By Arthur Colby

During the seminar, papers were presented regarding social influence in the development of future rehabilitation planning followed by discussion where the scholars experessed their own parochial interests and their perspectives of the future. Discussed were the viability of demographics and the census questioning process which leads to an individual being considered a statistical entity, and some of the consumers informed the attendees that individuals who have a handicap or a disability should be considered a member of a minority group called "handicapped." The Scholars were told that people with conditions considered a handicap consider themselves to be a minority and an oppressed group of people.

Thoughts were expressed during this seminar that demographics could be utilized to show the availability to potential employers of the numbers of persons with disabilities who reside in a specific area. These figures could then be used in a parity analysis to ascertain whether or not a specific company is properly utilizing the potential of the disabled work force effectively. Coupled with this concept was the suggestion (made by a few) that job providers, that is, business and industry, should somehow be fined for their failure to properly employ disabled workers. This concept coupled with the suggestion that utilizing the demographics business and industry should then be required to establish numeric representation and hiring quotas for disabled people, which, when not met, would also subject the employer to fines.

From my perspective, I questioned whether such issues would truly result in the desired end of the rehabilitation cycle, that, is more meaningful, competitive employment. The concept of having more legislated federal government intervention into the business affairs of the employers' world, I am positive would have an adverse impact on potential employees who might be disabled. Legislating the employment community into becoming a reluctant bridegroom would set aside the strides which have been made in this decade in accessibility, accommodation, and the total hiring process. Business does not need further burdens from legislated acts and/or federal mandates. It does, however, need the opportunity to meet the challenges of the future by developing programs which will provide a greater opportunity for competitive employment.

I know many employers are ignorant of the in-house perceptions found within the field of rehabilitation. I feel the most one can expect is to find an enlightened employer who is striving to employ the best qualified individuals to perform the Company's work regardless of their impairment. To suggest to this employer and the rest of the business and industry community that the disabled are desirous of being identified as a minority and wish to be counted as a minority seems, I'm sure, ludicrous to the federal contractor who, in meeting the requirements of Section 504 of the Rehabilitation Act, has asked his/her employees and the applicants for employment to come forward and self-identity if they feel they are handicapped or need special accommodations when most contractors have already discovered persons with disabilities do not self-identify. In fact, the disabled employee does not come forward to self-identify nor do disabled applicants for employment self-identify. Employers have been told by individuals with disabilities they do not wish to be assigned a stigma and have compared it to being tagged with another burden they do not wish to carry.

My personal experience tells me persons with disabilities only wish to ensure their needs are properly accommodated and their condition is not waved as a flag in their employer's face. The concept of being handicapped should ensure that a different kind of status **called minority** only furthers the perception of a segregated society in the eyes of those who place them in that category. I have been told by individuals active in the independent living movement they have a fear the independence offered by living with and for your peers in one central location may have elevated them on the ladder of socioeconomic success, but it has carried with,

it a negative in that they have now become a segregated community still dependent upon their surrounding neighbors.

I talked to a computer programmer who is a wheelchair user and he expressed concern that we, in this country, have "done a number on ourselves" and we are not happy as a people until we have put some form of identifying tag on everyone or everything we come in contact with. He felt we, as a society in America, have, through inference or association or by legislation, devised a large national pegboard on which all people could be categorized starting with whether or not the individual is a male or a female, young or old, white, black, yellow, Catholic, Jew or Moslem, etc., to even categorizing levels of education and towns of residency. He states he is disgusted because he only wants to be considered a **computer program analyst,** not a **disabled** computer program analyst.

I think when we look to the future and look at the social influences which will be affecting our future we must look at those influences which will affect business and industry. The future of rehabilitation as it applies to employment is dependent upon rehabilitation planning which ensures that job placement is one of the keys to a **successful rehabilitation program.** Business and industry are an integral part of the placement process. It is incumbent upon the rehabilitation community to be better prepared for the future than they were in the past so they may assist business and industry in being prepared for the **placements of the future.** A rehabilitation community needs not only to serve its clients, but also to serve the business community which provides the competitive employment. This means rehabilitation professionals and consumers need to be aware of the changes occuring in the job marketplace and be able to foresee new trends in employment which will require skills and training not performed before, to better provide qualified individuals with disabilities, and by so doing, enhance the chances of competitive employment for qualified disabled individuals. The rehabilitation community needs to address **its role from a marketing perspective.** A business analysis needs to be performed of where the socioeconomic growth and development trends can be identified. Using that information, it will provide the best qualified applicants for the emerging jobs in business and industry. Instead of adding additional burdens onto business, the rehabilitation community could better utilize their resources by approaching business to help them define and establish programs which will benefit business, and, by so doing benefit those needing rehabilitation services and eventual job placement. I suggest the goal of rehabilitation in the future is not unlike the goal of rehabilitation in the past, that is, to provide the **best possible candidates for the competitive work environment.** The successful programs will be based on a better understanding of the needs of the business community and based on a willingness to work with business and industry to develop mutually beneficial programs which will strive to provide more meaningful employment for qualified individuals who are disabled.

Economics, Rehabilitation and The Post-Industrial Society

By Raymond A. Ehrle

Employment quotas, more laws, appeals to charity and goodwill, application of bandaids to serious problems, political horsetrading, stopgap measures! I would argue that the only hope for mankind is through a long-term evolutionary process manifested by consciousness expansion by individuals. I would further argue that economic justice is a practical precondition for the attainment of such higher levels of consciousness.

The Current Scenario

The current scenario suggests that "we cannot get there from here." In fact the only place we can get to from here is to more meaningless employment and consumerism. Meaningful work is one of the avenues to consciousness expansion according to Hindu tradition (Mascaro, 1978). "Work is love made visible," according to Gibran (1963). However, Toffler (1982) has commented on the depersonalization that occurs when the worker is separated from the object of his efforts. The work is no longer meaningful.

Twenty years ago Henry (1965) reported that almost two thirds of the labor force were engaged in routine work requiring little education or initiative. They were largely concerned with raising

their standards of living and grasping for security. He states (p. 37):

Most American workers have learned to put the constantly rising standard of living in place of progressive self-realization.

He concluded that emotional satisfaction of cooperation, communion, joint problem solving, creative use of time and exercise of initiative, were denied in our occupational culture -- instead of work being a socializing activity it had become desocializing. Workplace demands (whether in factory, bank or small appliance repair shop) cut people off from their most significant emotional involvements. And the move away from smokestack to high tech industries does not change this situation.

Consequently, according to Henry, it is only through the deliberate creation of needs that our culture is permitted to continue. The system lowers our defenses against inner compulsions to express insatiable needs while harnessing human effort to the very machines that nourish the consuming appetites. **Homo consumens** -- man the consumer -- is born to feed on the products of the machine that he is conditioned to tend and which leads to further depersonalization.

We are taught that the necessities of life are scarce and that we must work and compete for them. (When we acquire these necessities, we will have learned to need still other necessities). The new video casette recorder is put on display. It can be ours if we pay a given number of tokens for it. The only way we can acquire such tokens (some call it money) is by doing a series of generally stupid nonsensical tasks i.e. by "working for a living." So it is **expected that everyone** (including the severely retarded, emotionally disturbed and physically handicapped) **must become a wage serf and "contribute" to society).** This is a central myth of our society -- rehabilitation clients and works, being part of society, do not question its validity at all.

But we **should** question the myth. During the past decade our society has produced 15 million new jobs as more women have entered the labor force. There is a big difference, however, in being employed and working hard and in being productive. I discussed this in more detail in another article (Ehrle, 1979) **We maintain a high level of employment by institutionalizing inefficiency thereby creating national inflationary pressures and individually meaningless work activity.**

Furthermore, not everyone is employed despite the myth. Forty-five percent of our population is actually in the labor force. Where are the others? We have invented ways to keep them out of the job market. Some are school children or graduate students. And there are prisoners, civil service pensioners, housewives, welfare recipients, military retirees. If we really **needed** 10 year old kids to mine coal they would be in the mines; if we really **needed** eighty year old grandmothers to sweep streets they would certainly be out there with a broom! In short we have devised many ways to keep people out of the job market, but with some degree of economic viability. Despite this reality the hallmark of being a first class citizen is to be employed.

It can be seen that we have created an essentially employment-income-consumer-demand treadmill. This treadmill requres that we function at the second and third levels of consciousness. [According to Kundlini yoga there are seven levels (Campbell, 1978) so humankind still has a long way to go.]

Permit me to briefly outline the number of parameters pertaining to seven levels of consciousness. At C_2 the individual functions at the physical level, is involved in the exercise of exploitive-manipulative power and dependent interpersonal relations. He/she is dominated by his body (and body image) and seeks to perpetuate himself physically through children. Such persons are concerned with "having" material things rather than "doing." Probably a majority of Americans are at C_2.

The C_3 or heroic person functions in a psychological environment and is driven by his ego into the exercise of competitive power. He is the leader/manager/professional oriented toward achievement and perpetuation of life by building a surplus -- of good works, money, professional contributions, etc. The C_2 person sings "Help me make it through the night"; the C_3 person sings "I did it my way."

The C_3 level person is aware of C_2 dynamics but the C_2 person (having had no C_3 experiences percpetions, etc.) does not comprehend those at the C_3 level. In other words higher levels of consciousness incorporate lower levels but the reverse is not true.

To summarize thus far, we have invented a system where everyone is supposed to be employed i.e. be a wage serf, no matter how personally nonsensical the task or how economically inflationary the result And then as **homo consumens** he is supposed to satisfy his inner hunger by purchasing the very material goods he has participated in producing. This closed loop of activity requires that he function at the second or third levels of consciousness.

The level of consciousness at which we function

determine how we perceive things, how we related, how we define our strengths and shortcomings, our needs and objectives. If we moved to a higher level of consciousness all these perceptions, institutions, beliefs, relationships would change.

Some New Realities

We are now confronted with a number of new realities. I will briefly discuss three of them: a) man's need for purpose beyond mere survival, b) society's need to create wealth, and c) man and society working together to build a system of economic justice.

Purpose Beyond Mere Survival

I believe that I am made up of three components -- my body, my ego (which often confuses itself with me) and myself -- the real me (Mascaro 1978). I know that my body is subject to entropy or death either suddenly or on a piecemeal basis. I also know that upon my death my ego will also perish. (Hence as it confuses itself with the real me it shouts "I don't want to die!") But the real me, the implicate force which existed before these other components became explicated will go on after they perish.

With this belief or myth I must then ask "What am I doing?," "Where am I going?" Some possible answers might be: You are here to be productive, to contribute to society. You are here to be a good citizen and consumer. Your are here on a fool's errand. You are a rat on a treadmill. You are the means to someone else's end. You are to be a good provider and parent. You are serving a life sentence pending execution. You are a toad in the Mississippi.

I cannot accept such answers which are conveniently provided by my ego. Rather I think mine and mankind's task -- whether doctor, lawyer, Indian chief, visibly or invisibly handicapped -- is to move to higher levels of consciousness. **The level of consciousness at which we function determines how we perceive things, how we related, how we define our strengths and shortcomings, our needs and objectives.**

At the fourth level of consciousness, the person functions at an essentially spiritual level with interdependent interpersonal relations and the exercise of integrative power. He perpetuates life by accepting that he is part of something greater than body and ego. Consequently the outcome of his perpetuation efforts is acceptance and contentment. His theme song is "Que sera sera" -- what ever will be, will be. This is probably the next stage in our evolution as a species; in any event **C, persons are not highly valued in our bureaucratic technocratic society at the moment because they are neither docile producers nor indiscriminate consumers.**

Moving from one level to another is not easy; it is not an intellectual exercise nor is it an exercise of willpower. It involves the notions of transcendence, transformation and qualitative change. It is a subject which has been studied by philosophers, psychologists, theologians and sage over the centuries. Hindu philosophy suggest that higher enightenment can be achieved through: a) thought and contemplation, b) caring and love, or c) meaningful work. Suffice it to say that depending upon what level of consciousness the person achieves, he will see himself, others, his situation, options, responsibilities, opportunities, limitations and alternatives in very different ways.

Fenderson (1984) quotes Naisbitt (1982) as follows; "The technology of the new information age is not absolute. It will succeed or fail according to the principles of high tech/high touch." Fenderson explains that as our work tasks move toward the manipulation of abstract symbols by a data mediated process for the production of goods and services, the human need for personal relationships, values and beliefs may be increased.

In short, as we move into this information age we must be prepared to move away from man as wage earner -- consumer. Fenderson concludes by stating (1984, p. 86):

> *...Unless the high tech environment of the future finds a strong counterpart in, for example, the human potential movement, the great and potentially liberated achievements of technology will be blighted.*

His position seems to be that the development of human potential (or for that matter, consciousness) is necessary to make technology work. My position would be that the desired end consequence is that of consciousness expansion with technology in the form of accumulated capital or wealth serving as a means to that end. Perhaps these means and ends will occur simultaneously and concurrently.

So how does all this relate to social justice in general and to employment in particular? It relates because **society accepts a more limited myth of work, productivity, consumption and economic society. This myth is tied to technology and bureaucracy -- the twin depersonalizing features of our time.**

Society's Need To Create Wealth

In the real world we must somehow be economically viable. This does not mean, however,

that we must convert all out wants to needs and become prisoners of these needs. And we must understand that economic productivity is a function of capital and labor -- the "Two Factor Theory" (Kelso & Hetter 1967). The architect-philosopher R. Buckminster Fuller (1969) estimates that 80% of productivity is attributable to capital while only 20% is attributable to our labor. As the years go by our labor actually becomes worth **less** and **less.**

Albus (1984) reminds us that the fundamental purpose of an economic system is not to create employment but to create and distribute real wealth. He states (Albus, p. 42):

> *The problem is not in creating enough jobs to keep everyone employed. The problem is in generating enough real wealth to meet the payroll.*

In commenting on this serious structural flaw Albus notes that (Albus, p. 40):

> *The fundamental problem is that income to the average family is distributed primarily through wages and salaries. The income distribution system in America -- and indeed in the entire industrialized world (including socialist and communist countries) -- is based on the labor theory of value, income is primarily determined by employment (that is, the sale of labor)....*

The idea that capital produces most wealth seems to conflict with today's situation in which 84% of corporate income is paid to labor while only 11% goes to capital (Burch 1976). Kelso (1978) argues that it is capital which produces affluence; labor can at best normally produce only subsistence. He concludes that as a result of this imbalance we have produced a permanent impetus to inflation, underemployment, and now productive "work."

If our real objective in life is to transcend our situation and move to higher levels of consciousness and personal growth, and if we are trapped in a myth that is composed of economic scarcity, escalating needs and the mandate to become a wage serf, and if there is another possible route to economic viability which will permit us to "Get on with it," we should explore this route. It concerns capital and access to capital or wealth.

Capital or wealth is the accrued store of centuries of effort, thought, trial and error, research and development, state of the art technology and information which may be manifested as plant and equipment, laboratories, money, education achieved and other resources. It is useful in that it contributes greatly to improved standards of living. This is true whether the society is one of state capitalism (as in the Soviet Union) or modified individual capitalism (as in the U.S.A.). The creation of wealth is a non zero sum arrangement because the economic pie actually grows larger at no one's personal expense. Hence, the importance of technology transfer to developing countries as they seek to enlarge their economic pies.

A New View of Economic Justice

If one had a stake in the accrued wisdom of the centuries, he would be able to create his own capital or wealth, and secure legitimate income through other than employment. The way to achieve this is through an employee stock ownership plan (ESOP) first proposed by Louis Kelso (1958).

In its simplest form the ESOP is an employee benfit plan like a pension plan or profit sharing plan which "qualifies" under the Internal Reverue Service Code. The ESOP, as a separate trust, borrows money from a bank or other lenders using the loan process. The ESOP purchases stock directy from the employer (if a new corporation) or from shareholders of an existing corporation.

When the ESOP borrows money the enployer guarantees to the lender that the ESOP wil repay the loan. Each year thereafter, the employe makes annual contributions to the ESOP in an amount at least equal to the ESOPs payments on the money borrowed. These amounts are then repaid by the ESOP to the lender each year.

The employers annual contributions are tax deductible to the employer; the employee-stockholder acquires shares without any up-front outlay of cash or reduction in take home pay. This approach calls for a) investment in anticipation of future earnings, and b) investment of pre-tax earnings. It results in a broadened base of ownership with each participant receiving a second income from earned dividends.

The second income feature is most impotant for this permits early retirement, phased retirement, part-time employment, released from wage-serf conditions, retirement portability and mobility, encouragement of meaningful work, labor mobility and, in turn, more legitimate job opportunities for all, including the handicapped.

If carried out extensively Kelso belices that ESOPs will stimulate so much economic growth that it may generally abolish welfare an make-work jobs as well. He concludes "the rols of the unemployed will fall and in due cours many government employees (released from the make-

work jobs) will be attracted by the advantages of working in industry under conditions providing opportunities for capital ownership, second incomes, and economic security.

Employee ownership has grown rapidly in the last several years and is the beneficiary of a number of recent federal laws. At the moment there are perhaps 7000 companies with ESOPs. They include E-systems, South Bend Lathe, Rath Packing, **Milwaukee Journal** and the Chicago and Northwestern Railroad which are majority owned as well as Eastern Airlines, Chrysler Corporation and Weirton Steel (Cowan, 1984). Further information may be obtained from: National Center For Employee Ownership, 927 Walter Reed Drive, #6, Arlington, VA 22204

A New Scenario

A new scenario calls for a recognition that wealth or capital is desirable. It should be created through new ideas, research and development and product and service development and marketing.

The wealth created would then be shared with employees through the use of ESOP (or related TRASLOP, CSOP and PAYSOP) plans. Capital would be "freed up" for additional research and development and employees would build their second income plans. Second incomes would make it possible for employees to retire earlier, or work part-time or phase out gradually. The net result would be a "loosening" of the labor market and creation of more job opportunities for handicapped workers, young people and minorities.

With more free time and a capital stake in the economy people might engage in meaningful creative activity, or serious meditation, contemplation or study, or engage in caring relationships.

Does this scenario envision all of us reaching Nirvana by next week? No. But it does open the door to possibilities.

□

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New Horizons for Developmentally Disabled Americans

By Jean K. Elder

During the last 25 years, far reaching changes have been made in the goals we have established regarding services for developmentally disabled Americans. Many of us remember when the birth of a developmentally disabled infant elicited expressions of sorrow and regret from family and friends and professional advice to quickly place the infant in an institution in order to assure that he or she would be adequately cared for throughout his or her lifetime and that he or she would not be an embarrassment or incumbrance to the parents. The same infant, if born today, would be expected to:

- *remain with his or her natural family during childhood.*
- *attend special education and, in some cases, regular school classes, and develop the skills and capabilities that will enable him or her to make the best use of his or her skills.*
- *live in the community as an adult, sometimes in a group home, and sometimes independently.*
- *actively participate in community activities such as cultural events, public transportation, and shopping.*
- *engage in meaningful, substantial work.*

These goals are being achieved for persons who are among the most severely handicapped members of our society. To be considered "developmentally disabled," a person must have a severe, chronic mental or physical condition (or combination of conditions) that was manifested before age 22, is likely to continue indefinitely, and which causes

substantial functional limitations in three or more of the following major life activities: self care, mobility, learning, economic self sufficiency, capacity for independent living, receptive and expressive language, and self-direction. In most cases, the disability originates at birth. Almost any known type of handicap can be the cause of a developmental disability e.g.; mental retardation, epilepsy, cerebral palsy, arthritis, autism, spinal cord injury, and heart disease. Many developmentally disabled Americans have multiple handicaps, e.g., mental retardation and a physical handicap, which greatly adds to the difficulty of working and taking part in community activities.

During the last 10 years, major shifts have begun to occur in legislation and programs in the United States which are necessary in order to meet more demanding goals for developmentally disabled persons.

During 1975, Congress passed the Education for All Handicapped Children Act which required participating States to furnish all handicapped children, regardless of the degree of their disability, with a free, appropriate public education. The changes in our educational system for seriously handicapped children have been dramatic. In 1975, about one million handicapped children in the United States were excluded entirely from the public school system and many others were being inappropriately served (United States Commission on Civil Rights). Today, few handicapped children are not receiving educational services.

In 1971, Congress authorized the Intermediate Care Facilities for Mentally Retarded Persons program, a program which greatly improved the quality of care being provided in institutions and enabled Medicaid funds to be used to support some community residential facilities. Recognizing the emphasis being placed on community based care, Congress, in 1976, amended the Social Security Act to permit Supplemental Security Income (SSI) payments to be made to publicly owned residential facilities with 16 or fewer residents. Previously, SSI payments could not be made to persons living in public residential facilities. The same Amendment (the Keys Amendment) also enabled States to make vendor payments to residential facilities on behalf of SSI beneficiaries without causing a reduction in their SSI benefits, and required States to set and enforce standards for residential facilities in which a significant number of SSI recipients resided, or were likely to reside. In 1981, Congress went further and amended the Medicaid Act to allow the Secretary of the Department of Health and Human Services to grant waivers to States to finance, through Medicaid, non-institutional services for elderly and disabled persons who otherwise would require institutional care. Most State have begun to take advantage of the waiver program to establish community based residents for aged and severely handicapped persons. In the future, additional changes in existing legislation to encourage **community based housing for aged and disabled persons** may be made.

As in the case of education, changes in the places of residence for developmentally disabled persons have been dramatic. From a peak of about 195,000 in 1967, the number of persons in State institutions for mentally retarded persons has fallen to about 128,000 in 1982 (Lakin, et. al.). More importantly, about 70,000 mentally retarded persons were living in group residences of fewer than 16 residents, or in semi-independent living situation, foster homes, boarding homes, or personal care homes in 1982 (Bruininks, et. al.). We anticipate that the number of mentally retarded persons living in community based residential facilities will exceed the number of mentally retarded persons living in large public institutions in a few years.

In the Rehabilitation Act of 1973, Congress directed State vocational rehabilitation agencies to give priority to serving "those individuals with the most severe handicaps," many of whom are developmentally disabled. Further encouragement for employing severely handicapped Americans came during 1980 when Congress authorized two special three year demonstration projects incorporated as Sections 1619(a) and 1619(b) of the Social Security Act. These demonstrations substantially reduced the work disincentives for SSI beneficiaries by providing special cash benefits and continuing Medicaid coverage for SSI beneficiaries who return to work and meet the conditions for participation in these demonstration programs. These two demonstration programs have been extended until June 30, 1987.

The Developmental Disabilities Act of 1984 established "employment related activities" as one of four priority services to be provided under the Basic Support Grants portion of the Act. "Employment related activities" are defined as" ... such services as will increase the independence, productivity, or integration of a person with developmentally disabilities in work settings, including such services as employment preparation and vocational training leading to supported employment, incentive program for employers who hire persons with developmental disabilities, services to assist transition from special education to employment, and services to assist transition from sheltered work set-

tings to supported employment settings or competitive employment."

By 1987, the Act makes it mandatory that "employment related services" be provided under the State developmental disabilities plan.

Information from numerous projects provides ample evidence that developmentally disabled adults can be placed in substantial employment. They have been employed in a variety of occupantions: horticulture, restaurants, car lots, and in many other types of businesses.

The Department of Health and Human Services instituted an initiative for the employment of developmentally disabled persons during 1984. The goal of the initiative was to place developmentally disabled persons in substantial jobs in regular places of employment. Part of the initiative was to enlist the corporate sector to help create employment opportunities and to hire developmentally disabled applicants. To assist in this effort, a direct mail campaign was conducted with businesses throughout the country. Over 1,100 employers indicated as interest in hiring developmentally disabled persons. In one instance, a chain of 200 restaurants committed itself to hire 500 developmentally disabled persons.

About 2,500 developmentally disabled persons were placed in substantial jobs through Projects with Industries (PWI) projects in 1984.

Altogether, it is estimated that 25,000 developmentally disabled persons were placed on substanial jobs in the Private Sector in 1984.

Despite these successes, the process of establishing a comprehensive system of services to employ developmentally disabled persons is in its initial phases. We anticipate growing pressure to expand this system in the future. Part of this pressure will develop as growing numbers of developmentally disabled persons are deinstitutionalized. In addition, the first waves of the expanded number of developmentally disabled children educated under the Education for All Handicapped Children Act of 1975 are beginning to **leave the school system.** Each year, about 90,000 developmentally disabled students leave school. In many cases, they will have difficulty obtaining adult services. Many will be placed in day care. These inadequate adult services do not meet the expectations of parents who have struggled to maintain their severely developmentally disabled children at home and who sent them to school to prepare them for useful lives as adults; nor do they meet the expectations of young developmentally disabled adults who have spent most of their childhood being prepared for meaningful adult lives.

One fact must be made clear. Many developmentally disabled adults require extensive and long-term services in order to be successfully employed. Evaluation and counseling, vocational training, physical restoration, a short follow-up, and closure will not be sufficient. Some examples of successful employment programs for developmentally disabled persons will illustrate the types of services that are needed.

- *Transitional Employment Enterprises in Boston, a PWI program, provides extensive services and placement of mentally retarded clients in business and industrial firms. However, the clients are provided long-term follow-up, counseling, and additional services as needed. The extended follow-up period may last a year and even longer.*
- *Physio Control, a Seattle area medical-electronics firm, trains mentally retarded employers to do assembly work. An experienced worker, initially paid by the state, supervises the work of these retarded employees. The presence of a special supervisor enables these employees to be integrated into jobs that would otherwise be carried out by non-handicapped workers.*
- *In Tucson, Beacon Foundation supplies a large car dealer with a clean-up crew of eight mentally retarded adults. Their work is supervised by a Beacon Foundation employee.*
- *In Oakland, Stepping Stones Growth Center has established several yard crews which go to different locations under the supervision of a trainer-supervisor.*
- *For developmentally disabled persons who are too severely handicapped to work in a competitive situation, the Specialized Training Programs that were initially designed at the Center on Human Development, University of Oregon, provide a work oriented alternative. These programs have generally been oriented towards electronic assembly and perform subcontract work in a workshop setting. These projects often hire several non-handicapped employees are continuously involved in productive work and have surprisingly high earnings, especially when it is realized that their alternative is to be placed in day care.*
- *Clearly, we need to expand the number of jobs available to, and within the capabilities of, developmentally disabled Americans. We believe that much can be accomplished in this regard by embarking on an information campaign to employers (and some professionals in the field) stressing the facts that most*

developmentally disabled adults can be productive workers with low turnover and high reliability, if provided the opportunity to work and the additional assistance they need.

- *We need to ensure that employers and persons responsible for developmentally disabled adults are awarded of the services that are available. Employers (and the rest of us) need to be familiar with the Targeted Job Tax Credit program, the Job Training Partnership Act, the services available from Vocational Rehabilitation agencies and State employment services, the services and assistance available from Developmental Disabilities/Mental Retardation agencies, and the services that are available from other private groups working for the employment of developmentally disabled persons.*

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Some Thoughts on Independence

By Margaret A. Nosek

Isn't independence what we're all after? It's the subject of a Declaration that started our country. it's on every school child's grade card under "citizenship." Its the reasen for nationwide, explosive celebration one day each year. Obviously, it is a highly valued trait in our society. All of us are expected to reach a certain degree of independence at a certain age in order to be considered well adjusted, mature, and successful. Isn't it a pity then, that in the 35 year history of rehabilitation services, including those designed to help people become well adjusted, mature and succesful, it is only within the last seven years that independence has been officially mentioned in connection with persons with disabilities, and even then, only as a separate and somewhat low priority goal.

Theory

Perhaps the reason for this inequity is that we have never really defined what we mean by "independence." To the person on the street, it means "nobody telling you what o do." Most heads of households will agree tha it means having the economic solvency to live n comfort. To a child it may mean climbing the sairs without having to hold on to anything. Much anthropological and sociological research needs o be conducted on what independence means to persons from different socioeconomic and cultural backgrounds. It's interesting to note that the child's definition in terms of physical autonomy has traditionally dominated rehabilitation (didn't someone once say persons with disabilities are "society's eternal children?").

While the importance of this subject warrants a full length philosophical dissertation, we must content ourselves for the present to begin by looking down some potentially fruitful paths. There must be factors which crosscut the influence which socioeconomic and cultural backgrounds have on perceptions or definitions of independence. Perhaps one such path would be to look at what the Epicuriean, Skeptic, and Stoic philosophers described as virtue: freedom from want, from unreasoned fear, and from the vicissitudes of life. On a more operational level, we need to look at the importance of such factors as freedom of motion, a stable and adequate source of income, freedom from physical and psychological harm, having a positive self-concept, interactions with significant others, the opportunity to initiate and engage in life quality productive activities, and the opportunity and ability to make responsible decisions. It is definitely time to move beyond the consideration only of autonomy in discussions of independence for people with disabilities, and address issues of interactions with the environment and perceptions of the self within that environment.

To fully understand this expanded concept of independence, it is important to realize that independence and dependence are not necessarily dichotomous. No person can be entirely autonomous physically or psychologically. Functioning in society demands a balance of independence and controlled dependencies. Dependence on human and/or mechanical assistance can be productive, whether it be on a car or a car pool for getting to work, or on a personal care assistant for getting out of bed and ready for work. It becomes unproductive and undesirable

when this dependence is not absolutely necessary and doing without it would cause no loss of quality of life for the individual or society. Physical independence may, in certain circumstances, be a greater negative than dependence. Consider the example of the severely physically disabled person who expends a large portion of his or her day performing all activities of daily living with the assistance of another person or a mechanical device makes a person dependent on that person or device. However, if there is a positive net result, and if the assistance is controlled by the disabled individual, then that individual can still be considered independent. An understanding of this would bring about massive changes in the way society views and treats disabled persons.

Practice

Earlier mention of the seven year history of independence in rehabilitation is a reference to Title VII and the 1978 Amendments to the Rehabilitation Act of 1973. This Title legislatively acknowledged independent living as a goal for severely disabled persons and allocated federal seed money for the development of a network of independent living programs. The legislation was passed as a direct result of a social movement, the independent living movement, in which disabled persons demanded the opportunity and training to control their own lives. Yet, in the eyes of rehabilitation professionals, independent living is seen as a goal separate from and secondary to employment. Somewhere, the concepts of independence and independent living have been forced apart by legislative and bureaucratic maneuverings. This gap must be closed.

What would happen if the expanded understanding of independence were accepted as the basis for all special education and rehabilitation services? Massive changes would, of course, take place since current systems are based on the goal of behaviorally measured productivity. For example, the atomistic techniques commonly used to train persons with learning disabilities, mental retardation, and physical disabilities in which specific, isolated skills are developed without regard to their relevance to independence or quality of life, would have to be reoriented and made parts of a much larger, holistic approach to education.

Programs which are funded according to the numbers of people treated rather than the quality of the treatment would have to be examined and given a whole new system for evaluation. Programs which are maintenance oriented rather than independence oriented would have to be totally restructured. A continuum would have to be formed of services designed to meet the individual's educational and supportive needs in order to reach and maintain their maximum level of independence and productivity.

If this expanded understanding of independence were applied to rehabilitation services, significant changes would need to be made in such areas as professional/client relationships, individual program planning, case management, the concept of closure and interagency cooperation and communication. Many new, progressive developments in the delivery of rehabilitation professionals with disabilities, the involvement of the client in program planning, and an increased emphasis on coordination with other state and local services, make it a discipline which is at least pointed in the right direction. In an ideal system, the delivery of medical and vocational rehabilitation services would become parts of a larger system which delivers a comprehensive spectrum of services for enhancing independence.

And somewhere down the line, even the limitation of only serving persons with disabilities will fall away. A full array of conditions and life situations prevent individuals from reaching their maximum quality of life potential; disability is only one. Everyone can benefit from educational and social services designed to help individuals live independently. When independence is fully understood and applied equally by the public to all people, then a new age of rational humanism will have dawned.

A Response to the "Changing Perception Of Disability and The Future of Rehabilitation" by Harlan Hahn

By L. Robert McConnell

This is a response to the chapter by Dr. Harlan Hahn and is presented in two parts. First, just general reactions and comments which may be considered, and secondly, from regarded policy implication concepts which are also tied into the Hahn approach. In general, I feel that the paper makes an excellent case for viewing many of the problems that handicapped individuals face in a social context as a minority group., Clearly, it would suggest a redirection and rehabilitation programming which may be producing for the field. There can be no debate that many of the problems that disabled individuals face are directly related to societal values and attitudes which manifest themselves in political, social, educational, employment, and environmental arenas. Some random thoughts follow:

★ While recognizing that disabled individuals may be viewed in the context of racial and ethnic minorities, one must also realize that the impacts of prejudice and the differences in societal reaction to various subgroups of the handicapped may be substantially different. It may, therefore, be useful to use the analogy that the handicapped are to a specific disability group as the concept of racial/ethnic minority is to a specific racial group. This concept recognizes that while most racial ethnic groups suffer from a degree of discrimination, the extent of prejudice and the nature of the given stereotype may be significantly different from one racial group to another.

★ The extent of deevaluation that may occur for disabled individuals is suggested to be related to the dominant cultural social values, i.e., intellect, physical structure, beauty, verbal skills, etc. (Vash, 1981; and Albrecht, 1976). Carrying this concept further may suggest that the degree of acceptability of a given characteristic may be related to the desirability of that characteristic as the dominant cultural value; the extent of discrimination in turn may be based on the extent to which one values the most valued characteristics.

★ Some of the work by Tringo (1970) suggests that there are degrees of acceptability, at least in terms of social distance scales, for various subgroups of disabled persons.

★ Most recent literature on the topic of attitude change with regard to disabled individuals suggests that both **knowledge** and **contact** is necessary to effect a change in attitude (Anthony, 1972).

★ We must be careful not to suggest the "functional limitation" and "minority" models as "either/or" options. The functional limitations concept is most widely used as a basis for eligibility for vocational rehabilitation services. It is in that sense used as a tool to develop individual prescriptive plans for the client. The minority group model recognizes that part of the problem lies in the environment but this does not negate the need for individual rehabilitation planning. The strength of the minority model lies in its recognition that individual rehabilitation planning cannot occur independent of a need to address societal barriers.

★ While recognizing that the impact of the discrimination affecting disabled persons provides a strong rationale for the minority group model, future planning cannot ignore the significant differences the disabled have as compared to other minority groups, i.e., heterogeneity, lack of common family culture, limits on assimilation (Wright, 1960), and the fact that the dominant view toward the disability is one of sympathy. Roth (1983) has suggested that the sympathetic view has not only fostered certain attitudes towards disabled individuals, but has also enabled a degree of financial support for the needs of this population which may be at risk with a minority/advocacy approach.

★ The current mood of the country appears to be a down playing of equal employment opportunity and civil rights for protected groups. It may be more difficult for disabled people to achieve the consideration afforded to other groups given this current environment.

★ Probably more important than with any other minority group, the question of terminology with

regard to disabled individuals operates as a strong counter productive force in achieving access to employment. Disabled persons have not yet adopted and identified a terminology which connotes self-pride and self-worth.

★ The disability movement has tended to be a white male, middle class movement. This will have important implications for its acceptability among other protected groups, i.e., minorities, females.

★ While environmental changes are possible and necessary to allow equity of access to many disabled individuals, making those environmental changes draws attention to the differentness of disabled individuals.

★ At least in the employment arena, cost is a factor which cannot be ignored (either actual or perceived). This is a factor that is unique to disabled as a minority group and in fact means that in many cases to assure an equity of treatment to disabled individuals is to provide different treatment for this poplulation than that afforded other job applicants.

Policy Implications

1. Practitioners in rehabilitation must also become experts in the areas of environmental accessiblity, job accommodation, laws protecting the handicapped, and assuring education and awareness of the general public. This speaks to an enlarged role for rehabilitation practitioners.
2. Strong civil rights enforcement is clearly necessary as society must be made to assure that existing laws and public policy are carried out. While a coordination between civil rights enforcement personnel and rehabilitation practititoners is necessary (and essential), these roles and responsibilities must remain separate in order to be effective.
3. Vocational rehabilitation eligibility criteria should be revisited and incorporate a consideration of environmental and attitudinal barriers as a handicap to employment along with functional limitations. The language of "limitation" should probably be deleted from the terminology surrounding eligibility decisions. The language itself suggests that it is the client's problem and not one of a larger society. I would suggest the phrase "barriers to employment."
4. The issue of cost cannot be ignored. Either tax incentives or other financial offsets must be available to employers so that hiring disabled workers makes good financial sense to the employer.
5. The disability movement must broaden its base to bring in other groups that are currently not strong supporters. The disability movement is at risk in making the same societal mistake that others have made, i.e., an elitist movement; alienating those of its members who do not see it as relevant. A conscious effort to involve women and minority handicappers will not only strengthen the numbers within the disability movement, but reduce the potential of competition with other protected groups who also seek a piece of the pie.
6. The employment problems of disabled individuals must be viewed in the context of comprehensive manpower policy in two ways. First, the disabled must be a conscious part of manpower policy of the United States; and two, a manpower policy for the disabled must incorporate a comprehensive approach which links job accommodation, education, civil rights enforcement, environmental accessibility, and client preparation and training.
7. The government must take a lead role, i.e., set the example, in the employment of disabled individuals and in the removal of architectural barriers.

□

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The Emerging Role of Disabled Hispanics

By Antonio Suazo

Historically, Hispanics have been in this country for many years. The Spanish colonists settled in the Southwest long before there was a Plymouth Rock or a Jamestown. The direct decendents of the Spanish conquistadors still live in northern New Mexico and other parts of the Southwest.

In employment, Hispanics have traditionally been "underqualified" or "overqualified." Disabled Hispanics, as with other disabled minorities, experience rejection not only because they are a member of a minority group, but also because they are disabled. Thus, the disabled Hispanic is in a state of "double jeopardy" when it comes to full integration into the mainstream of American society.

It is important today to understand that the term "Hispanic" represents diverse populations that include, in large numbers, Mexican-Americans, Cubans, Puerto Rican mainlanders and Puerto Rican islanders. As noted by Linsky, Arnold and Hanoch (1983) cultural differences can be assumed to exist among the various Hispanic populations. Further, it seems reasonable to hypothesize that such cultural differences between and among Hispanic populations are historical in origin, but are also affected by geographic region, socioeconomic status, educational level and rural-urban locale. It becomes imperative, therefore, to scrutinize closely all research which presumes to reflect the "Hispanic" culture.

Hispanics are a growing population in the United States. The recent 1980 census indicated a substantial increase from previous years. They now number in excess of 14½ million -- a significant proportion of the U.S. population -- and growing every day due to fertility and immigration.

Hispanics are young and urban with a variety of economic and social problems. Educational problems are serious with a high school drop-out rate that is double the national average. Language and cultural barriers frequently serve as inhibitors in their efforts towards total assimilation.

Data on the number of Hispanic disabled is practically non-existent or sketchy at best. Based on limited data and using inferential methods it is estimated that there are some 2.5 million Hispanics of working age who are disabled. However, only a scant 25,000 persons of Hispanic origin were rehabilitated by public programs in 1981.

The Hispanic disabled represents a real challenge to rehabilitation professionals and administrators. If we are to provide meaningful rehabilitation services, some of the cultural characteristics discussed by Rivera (1) and others as factors in rehabilitating disabled Hispanics are:

La Familia: *The Spanish family provides the primary support system for the individual. Besides the many positive factors of family support systems this can also result in overprotectiveness and tends to dilute efforts towards independence by disabled individuals.*

Personalismo: *This relates to the personnel network among Hispanics as opposed to the dependence on the direct institutionalized delivery systems. The absence of Hispanics in key positions mitigates against an effective delivery system because of their reliance on personal contacts and acquaintences.*

Machismo: *The male attitude of full responsibility for behavioral guidance of the family. Within this context the male member of the family is responsible for providing resources to the family and for making major decisions affecting the family members.*

La Palabra: *"A man's word is his honor." The commitment to a verbal contract is very important to Hispanics. This characteristic, performance based on one's word as opposed to written contracts, is of paramount importance and should be considered in any rehabilitation program that is initiated in behalf of Hispanics.*

Language: *There is limited information available in Spanish regarding the vocational rehabilitation program. The communication barrier is critical since there are so few bilingual and bicultural professionals in rehabilitation.*

Clearly, the emerging issues in our efforts to serve this special population revolve around (1) existing barriers to rehabilitation; (2) development of innovative service delivery systems and (3) basic research issues. Of particular concern, however, to rehabilitation practitioners is the need to develop specialized programs to overcome immediate barriers to their rehabilitation and employment.

A paper by Orlando (1983) summarized the situation in the following manner. "There appears to be an underutilization of rehabilitation services by disabled Hispanics. The reason for this is the bar-

rier to access to these services. The solution is the need for outreach and advocacy. Rehabilitation counselors need to go into the community (including the home) and get acquainted with community leaders, and the clergy and inform them of what rehabilitation services exist for disabled persons and how to access the system. All too often potential clients do not understand the application process to enter a vocational rehabilitation program nor their rights as citizens under the rehabilitation laws and regulations."

One obvious area which needs immediate attention is the need to train more bilingual, bicultural professionals and place them in areas where there is a high concentration of Hispanics.

Some conclusions drawn by Lafitte (1983) include the following: current training programs in rehabilitation might take the initiative by introducing into their curriculum undergraduate and graduate courses in the language and culture of Hispanics. Such course offerings would be of significant value to those rehabilitation training programs located in densely populated areas such as the southwestern United States, metropolitan New York City, Southern Florida and Puerto Rico. An assertive and well organized recruitment program to attract Hispanics into the rehabilitation training program are also vitally needed according to Lafitte.

A conference on the Special Rehabilitation and Research Needs of Disabled Hispanic Persons (1983) provided a variety of recommendations regarding rehabilitation issues and research needs. Several of these needs are listed for your information, as follows:

1) More accurate data on the numbers, types, or disabilities, and acceptability of services in order to design effective rehabilitation services for the disabled Hispanic person.

2) Research on the effectiveness of various rehabilitation approaches to eliminate barriers which preclude acceptance and utilization of rehabilitation services and technology by this population.

3) Research of innovative approaches to extending rehabilitation services to migratory workers and those disabled who live in rural areas.

4) Research should include elderly Hispanic persons whenever rehabilitation issues are addressed.

5) Studies of the development of mechanisms for involving the disabled Hispanic student in the rehabilitation process prior to the end of his or her secondary school education.

The above are but a small number of ideas for programs that need to be undertaken, but one other important need exists. The inability of many Hispanics to communicate easily in English seriously obstructs access to rehabilitation services and employment.

For many disabled Hispanics, the educational stability so essential to learning English is often missing. This problem is two-fold and solutions must be sought from a dual perspective, i.e., the knowledge of English as a second language must be pursued and at the same time, more bilingual and bicultural services are needed from the providers of rehabilitation services. This is certainly an attainable goal by the year 2000.

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Master List of Switzer Scholars

FIRST SWITZER SEMINAR

Cleveland, Ohio -- May 20-23, 1975

"Pathology, Impairment, Functional Limitation And Disability -- Implications for Practice, Research, Program and Policy Development and Service Delivery"

Fred Addison
Lithonia, Ga.
Olive Banister
Cleveland, Ohio
Monroe Berkowitz
New Brunswich, N.J.
Richard D. Burk
Dayton, Ohio
Barry P. Craig
Charlottesville, Va.
Raymond A. Ehrle
Washington, D.C.
Rod Ferrell
Washington, D.C.
August Gebrke
St. Paul, Minn.
Carl V. Granger
Boston, Mass.
Lawrence Haber
Baltimore, Md.
Joseph Hunt
Arlington, Va.
William A. McDowell
Huntington, W.V.
Joseph Moriarity
South Charleston, W.V.
Saad Nagi
Columbus, Ohio
C. Esco Obermann
Afton, Minn.
Leonard G. Perlman
Rockville, Md.
Dean Taylor
Richmond, Va.
E.B. Whitten
McLean, Va.

SECOND SWITZER SEMINAR

New York, New York -- January 17-19, 1977

"Rehabilitation of the Older Blind Person: A Shared Responsibility"

Willis W. Atwell
Washington, D.C.
Duane Balentine
Little Rock, Ark.
Mary K. Bauman
Philadelphia, Pa.
Robert Carolan
Providence, R.I.
William T. Coppage
Richmond, Va.
Dorothy Demby
New York, N.Y.
S. Saul Freedman
New York, N.Y.
George Gillispie
Washington, D.C.
Helen Gromann
Newark, N.J.
Leonard G. Perlman, Coordinator
Rockville, Md.
Douglas E. Inkster
New York, N.Y.
Ruth Kaarlela
Kalamazoo, Mich.
George A. Magers
Washington, D.C.
Betty Maloney
Brooklyn, N.Y.
Melvin Saterbak
Minneapolis, Minn.
Irving P. Schloss
Washington, D.C.
Daniel Sinick
Washington, D.C.
Bonny Russell
Atherton, Calif.
Joseph Hunt
Chairperson

THIRD SWITZER SEMINAR

Denver, Colorado - December, 1978

"The Role of Vocational Rehabilitation in the 1980's Serving Those With Invisible Handicaps Such As Cancer, Cardiac Illness, Epilepsy"

Olive Banister
Cleveland, Ohio
Abraham Brickner
Detroit, Mich.
Sterling B. Brinkley
Washington, D.C.
Lawrence D. Burke
Bethesda, Md.
G. Fred Cromes, Jr.
Dallas, Tex.
William Gellman
Chicago, Ill.
John Goldschmidt
Chicago, Ill.
Hank Graden
Raleigh, NC
Morris C. Hansen
Salt Lake City, Utah
James F. Garrett, Chairperson
Washington, D.C.
Lawrence C. Hartlage
Augusta, Ga.
Betty Hedgeman
New York, N.Y.
Melvin J. Kraat
Worchester, Mass.
Robert M. Levenson
Seattle, Wash.
matthew Maxon
Dallas, Tex.
David I. Mostofsky
Boston, Mass.
Joyce Pigg
Redwood City, Calif.
Judy Spoium
Denver, Colo.
Jerry L. Starkweather
Des Moines, Ia.
Leonard G. Perlman, Coordinator
Rockville, Md.

FOURTH SWITZER SEMINAR

New York, New York -- February, 1980

"The Rehabilitation of the Mentally Ill in the 1980's"

Sheila H. Akabas
New York, N.Y.
William A. Anthony
Boston, Mass.
Les Brinmson
Durham, N.C.
Doris W. Dennard
New York, N.Y.
Nancy Downes
Laurel, Md.
Joseph Fenton
Washington, D.C.
Steven M. Fishbein
Princeton, N.J.
Robert J. Grantham
Buffalo, N.Y.
Durand F. Jacobs
Loma Linda, Calif.
Herbert B. Mosher
Topeka, Kan.
John Pelletier
Quincy, Mass.
James E. Ramaeur
Central Islip, N.Y.
Robert D. Ray
Chicago, Ill.
Luther D. Robinson
Washington, D.C.
Marshall Rubin
Miami, Fla.
James R. Schmidt
New York, N.Y.
Brockman Schumacher
Carbondale, Ill.
Sam Silverstein
Rockville, Md.
Mildred Mitchell-Bateman, Chairperson
Huntington, W.V.
Leonard G. Perlman, Coordinator
Rockville, Md.

FIFTH SWITZER SEMINAR

New York, New York -- March, 1980

"International Aspects of Rehabilitation Of Disabled Persons: Policy Guidance for the 1980s"

Norman Acton
New York, N.Y
James R. Burress
Washington, D.C.
Rodrigo Crespo
Montivideo, Uraguay
Bruce M. Curtis
Houston, Tex.
Gregory Dixon
Washington, D.C.
Barbara Duncan
New York, N.Y.
George A. Engstrom
Washington, D.C.
Donald E. Galvin
East Lansing, Mich.
Susan Hammerman
New York, N.Y.
Marceline E. Jaques
Buffalo, N.Y.
Jeanne Kenmore
New York, N.Y.
Leonard G. Perlman, Coordinator.
Rockville, Md.
Fred J. Krause
Washington, D.C.
Michael Marge
Syracuse, N.Y.
Martin E. McCavitt
Washington, D.C.
Mercedese M. Miller
Washington, D.C.
Elizabeth Pan
Falls Church, Va.
James S. Peters, II
Hartford, Conn.
Robert B. Ransom
Washington, D.C.
G. Allan Roeher
Ontario, Canada
Robert Ruffner
Washington, D.C.
Howard A. Rusk
New York, N.Y.
James F. Garrett, Chairperson
Washington, D.C.

SIXTH SWITZER SEMINAR

Washington, D.C. - November 16-18, 1981

"Women and Rehabilitation of Disabled Persons"

Edna Adler
Washington, D.C.
Bobbie Atkins
Milwaukee, Wisc.
Joan Thompson Barker
Versailles, Ky.
Martha Carrick
Atlanta, Ga.
Susan Flowers Dixon
Washington, D.C.
Billie Elder
Little Rock, Ark.
Yetta Galiber
Washington, D.C.
Sheila W. Hackett
Washington, D.C.
June Lacatta
Columbia, S.C.
Kathaleen Arneson, Chairperson
Falls Church, Va.
Chris Lord
Springfield, Va.
Frances Lowder
Arlington, Va.
Elizabeth Minton
Dunbar, W.V.
Thelma Schmones
New York, N.Y.
Harold Snider
Washington, D.C.
Miriam Stubbs
Washington, D.C.
Denise G. Tate
East Lansing, Mich.
Evelyne R. Villines
Des Moines, Ia.
Carolyn Vash
Atladena, Calif.
Leonard G. Perlman, Coordinator
Rockville, Md.

SEVENTH SWITZER SEMINAR
Washington, District of Columbia - November 10-12, 1982
"Rehabilitation in the Public Mind: Strategies of Marketing"

Ethel Briggs
Washington, D.C.
Nancy Belohavek
Topeka, Kan.
Shirley Bonnem
Philadelphia, Pa.
Robert Druckenmiller
Washington, D.C.
Frank Bowe
Cedarhurst, N.Y.
Craig Colvin
Knoxville, Tenn.
Eunice Fiorito
Washington, D.C.
Carol Hills
Boston, Mass.
Roberta Housman
Bronx, N.Y.
Gary Austin, Chairperson
Carbondale, Ill.
Gini Laurie
St. Louis, Mo.
Jerome R. Lorenz
Carbondale, Ill.
Frank Sell
Gastonia, N.C.
Terence A Shimp
Columbia, S.C.
Jinny Spann
Dunbar, W.V.
Peter Vail
Norman, Okla.
Jack Victor
Albertson, N.Y.
Henry Viscardi, Jr.
Albertson, N.Y.
Lawrence E. Warnock
Boston, Mass.
Leonard G. Perlman, Coordinator
Rockville, Md.

EIGHTH SWITZER SEMINAR
Washington, District of Columbia - November 16-18, 1983
"Technology and Rehabilitation of Disabled Persons In the Information Age"

Susanne Bruyere
Seattle, Wash.
Thomas Counter
Silver Springs, Md.
Ted Daniels
Washington, D.C.
Olivia Diaz
Pasadena, Calif.
Valerie Ellen
New York, N.Y.
Robert Gilmore
Crofton, Md.
Alan Hofmeister
Logan, Utah
John H. Leslie
Wichita, Kan.
Donald Linkowski
Washington, D.C.
Kali Mallik
Baltimore, Md.
Gary F. Austin, Chairperson
Carbondale, Ill.
Wilman A. Massie
Annandale, Va.
Don McLaughlin
Morgantown, W.V.
Gopal Pati
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For the Ninth Switzer Memorial Seminar

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Summary of Recommendations

The following is a summary of the recommendations and implications for action developed by the Switzer Scholars as they relate to the topic of Chapter Five. (The Recorder was Anna Fay)

1. Recommendations/implications that would enhance service delivery:

That counseling support systems be developed and available to parents prior to and following the birth of a disabled child.

That there be **equity of access** to the counseling support system irrespective of racial, ethnic or economic condition.

2. Recommendations/implications for policy; and program development

That there be assurance of adequate health care for all disabled individuals.

That parents /families be provided additional funds to offset the cost of long-term care for children with disabilities.

That policy, program and legislative decisions affecting people with disabilities must include them in the decision-making.

That persons with disabilities be represented on all ethical committees in all health care facilities.

That the rehabilitation and disabled communities provide technical assistance to State Child Protection Systems in their implementation of PL 98-457, (Child Abuse Amendments of 1984).

That there be a national ethical committee appointed to relate to the issues arising from PL 98-457 involving funding of Medicare, Medicaid and other health care financing, and that this committee include participation from persons with disabilities.

That financial supports, including SSI, Medicaid, and other financial incentives, be provided to parents of children with disabilities.

3. Recommendations/implications for training of staff, the general public, etc.:

That medical school curricula and continuing medical education must address the issue of disability within a **social context,** which includes knowledge of service resources and the involvement of consumer and advocacy organizations.

4. Recommendations/implications for needed research:

There is a need to explore the legal implications of withholding medical care due to one's inability to pay the cost of such care.

That there be follow up studies on infants for whom it was decided **not to withhold treatment** to determine the social and economic quality of their lives.

That the National Institute of Handicapped Research and/or National Institutes of Health support studies of bio-ethical issues relating to a variety of treatment and service decisions affecting the interests of persons with disabilities.

5. Recommendations/implications for legislation – Federal, State, Local:

Legalize the status of the "Living Will" in all 50 states. The "Living Will" is a document written by an adult which contains his/her instructions with regard to the extent of **life support systems** they wish to be used in a given medical situation.

That the rehabilitation and disabled communities monitor and lobby their state legislatures for the proper implementation of PL 98-457 (Child abuse Amendments of 1984.)

6. Recommendations/implications for any areas not categorized in above listing:

That in all the advisory and decision-making capacities referred to in these recommendations, efforts must be made to actively and vigorously develop outreach programs to include minority persons with disabilities; that strategies be developed to include minority persons with disabilities in the decision-making process to ensure that appropriate services are available.

It is recognized that Congress has enacted legislation creating a standard for providing medically indicated treatment (PL 98-457). Note that this legislation also creates **substantial burdens for families and society,** unless Congress also establishes a disability allowance and other substantial supports.

Despite the demands on the national and federal scene, her presence was almost ubiquitous in behalf of program development and extended services to needy people. On a regional, state or local level, be it public or voluntary services, if it were in the interest of rehabilitating those in need, somehow, she would "arrange to be there."

The WHO'S WHOs has chronicled her many national and international awards. Also recorded are her presidencies of many organizations including NRA, whose members and their efforts she held in high esteem. But she did not reach the heights of her ability when she was made the first Administrator of the Social Rehabilitation Services, not when she retired from the position, nor when she became internationally involved in the World Rehabilitation Fund. Instead, she found her greatness when she touched each of us bringing our full humanitarian efforts and qualities to the fore in behalf of disabled and disadvantaged people. While readily recognized as a truly great administrator in the classical sense of the word, her true capacity and ability can only be appreciated when we realize that these accomplishments sprang from an inner expression of sensitivity, emotional refinement and dedication to serve all less fortunate people. Her egalitarian qualities were not contrived but spontaneous, stemming from love and respect for all living things.

All of us in NRA and in rehabilitation and all handicapped people have had better, more meaningful, and more productive lives because her presence and her being were sufficiently large to embrace and accept us as we are and help us better understand where we should be.

What more can be said than that we had the joy and privilege of knowing her?

This memorial tribute is quoted from I. B. Whitten, Journal of Rehabilitation, November-December, 1971

Mary E. Switzer Memorial

To perpetuate the memory of a great women and a great leader in the field of Rehabilitation by establishing a memorial that will expand and enrich services to handicapped individuals

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